DEVELOPMENT AND EVALUATION OF A COMMUNITY-BASED REHABILITATION PROGRAMME FOR PRE-SCHOOL DISABLED CHILDREN IN GUYANA

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A thesis submitted to the Institute of Education, University of London, for the degree of Doctor of Philosophy.

December 1988

A B S T R A C T

There are millions of disabled persons in the world. An Institutionally-Based model of rehabilitation alone cannot meet the challenge. The World Health Organisation (WHO) have offered Community-Based Rehabilitation(CBR) as an alternative approach. CBR advocates a simplified form of rehabilitation , mobilising resources that exist within the community.

This project examines the relevance and effectiveness of a CBR project implemented in two rural areas of Guyana over a two year period.

The programme is facilitated by a Local Supervisor (LS) who works in the child's home alongside a family member. Two groups of LSs were recruited, one comprised 26 volunteers from the community and the other constituted 25 nursery teachers. Disabled children were identified by surveys and by referrals by parents and professionals.

A Multiple-Baseline Design was adopted to assess the child's progress. The children were assessed fortnightly on the Portage Checklist and pre, post and at a 6 month follow-up on the Griffiths Test of Mental Development. The quantitative gains were balanced with a qualitative analysis of questionnaire and interview data.

The majority of parents participated actively in the programme, however for others the role was too demanding.

An analysis of Portage scores revealed a gain of .67 items per month per subtest under baseline conditions, 1.95 items under treatment conditions and 1.02 items under control/ follow-up conditions.The Griffiths results were significant at post-test and 6 month follow-up test (p= .01 for both groups of children.) The mothers observed changes in themselves feeling more relaxed and confident, and less depressed. The changes were however more characteristic of the 'volunteer' mothers than the 'nursery' mothers. 4/26 volunteers and 12/25 nursery teachers were not involved in the programme.

Progress was seen in the physically and mentally handicapped children, others with severe speech and hearing problems may need more intensive help than that offered by this approach.

A local committee created a resource unit for the disabled children of their area. The cost of the programme, excluding the cost of referral services, was £27 per child, per year.

The thesis analyses; key features of introducing an innovation; ways in which the WHO approach was modified; limitations of the CBR model, and suggestions for further study.

D E D I C A T I O N

To Liam and Cairan for their tolerance of the closure of their father's door on so many occasions.

No portion of the work referred to in this thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institution of learning.

C O N T E N T S

L I S T O F T A B L E S

TABLE PAGE

L I S T O F F I G U R E S

A P P E N D I C E S

A C K N O W L E D G E M E N T S

It is customary to acknowledge the help of one's supervisor in a thesis of this nature. However a few words cannot adequately record the debt due to Brahm Norwich for his invaluable insights, supervision and guidance.

Geraldine Maison-Halls was an invaluable fellow co-ordinator of the CBR programme in Guyana. Other rehabilitation therapists made important contributions in teaching on the programme. The Georgetown Association of Parents of the Mentally Retarded was a key resource group who remained involved in all aspects of the project. The Village Health Committee of Grove-Diamond have given a life to the programme beyond the research with the establishment of a resource unit for the disabled children of their village.

The administrative support of the Institute of Adult and Continuing Education and the Ministry of Education in Guyana is gratefully acknowledged. Material support from the Canadian International Development Agency (MAF 86/87 2413 A), and the Universities of London and Guyana ensured that finance would not be a barrier to the project. My employers, the University of Guyana, were generous in the study leave they granted me in pursuing this research.

The Volunteers and the Nursery Teachers gave freely of their time often under difficult circumstances. The parents were invariably hospitable and gracious and kindly forgave us for the mistakes we made.

Natalie Heyraud spent many weeks in helping to produce a video on the project which was subsequently featured on national television.

Roy McConkey, Klaus Wedell, Pam Zinkin and Peter Mittler found time to offer advice and critique early outlines of the project.

My wife, Pamela, was a never-ending source of encouragement, to her I owe a great deal.

CHAPTER 1: CHANGING TRENDS IN REHABILITATION

1.1 Magnitude of the problem

A series of international reports (UNICEF, 1980; UN, 1982; Rehabilitation International, 1981) estimate 10% of the population to be disabled. Surveys in developing countries (LDCs) suggest this may be a conservative estimate. The Zimbabwe National Disability Survey, based on in-depth interviews conducted in 23 different locations by specially trained personnel, identified 15% of the population as disabled (Davies, 1981). A total population survey of the children aged 5-14 years in one village in Nigeria revealed 25% of the population as having some form of handicap (Okunade, 1981). Three extensive surveys in Nepal identified 10% of the population as suffering from mental handicap (Gudalefsky,1985). A British survey of 1000 persons found 27% of the population to have a disabled relative (Weir, 1981).

The precise numbers could be debated, however the need is clear. Disability creates a considerable social, economic and emotional cost to the disabled person's family and the wider community. Without effective rehabilitation disabled persons will lead unhappy, dependent lives, and they will remain burdens to themselves and to society. The burden falls disproportionately on those in the developing world where disabled persons live without dignity, victimised by beliefs that they are possessed by evil spirits or proof of divine retribution (Gudalefsky, 1985; WHO, 1982:3).

An estimated 75% of the disabled population live in LDCs,however if the present trends of poverty, ignorance, superstition and fear continue the figure may rise to 80% by the end of the century (Noble, 1981).

1.2 Can rehabilitation be a priority in LDCs?

Hammerman and Maikowski (1981) present an economic analysis of rehabilitation illustrating how disability perpetuates underdevelopment in LDCs by the failure of those nations to harvest the productive capacities of all their citizens. However there can be little economic rationale for rehabilitation in LDCs where already a high percentage of the educated, able-bodied population, are without employment (Botswana Red Cross Society, 1980).

The present model of rehabilitation, based on institutional care, would absorb more than the total health budget of most LDCs if serious attempts were made to meet the needs of all disabled persons. Is it therefore realistic to expect LDCs to direct scarce resources to expensive services for a minority?

If the developing world is to give a higher priority to the disabled it must be in the name of a just society, no nation can morally or practically ignore a problem affecting such numbers. The danger is that rehabilitation may be given a low priority because the goals of overcoming pain, suffering and dependency do not fit easily into equations of cost-benefit analysis (Rehabilitation International, 1981). Misery cannot be tolerated simply because it is not easy to quantity. Morally governments have to respond, however for practical reasons more economical approaches will need to be explored to meet the magnitude of the task.

1.3 Not meeting the challenge

The lack of progress in this area can be illustrated by two WHO reports on rehabilitation which have almost exactly the same recommendations despite being written five years apart (WHO, 1976; WHO, 1981). Existing services are reaching only 2% of those in need (WHO, 1982:3; Periquet, 1984:9; Mendis, 1988;

Moyes, 1981:13). Rehabilitation is regarded as inaccessible in rural areas (Thorburn & Roeher, 1983; Arnold, 1986). The international situation is thought to be no better now than 25 years ago (UNICEF, 1980:221).

The bleak international assessment is based on a series of reports across the continents. In Africa, Nyathi (1983) estimated that only 2% benefited from the rehabilitation facilities which are all based in urban areas of Zimbabwe. McPherson (1985) notes a similar figure for the number of deaf children attending special schools in Nigeria. The International League of Societies for Persons with Mental Handicap (ILSMH) carried out a continent-wide review of the coverage of special schools of children with specific learning disabilities or mental handicap, the figures recorded were: Nigeria 0.7%, Zambia 2.9%, Botswana 4.7% and Kenya 4.5%. Moreover these figures were regarded as 'rather generous estimates' (Serpell, 1983:16).

The pattern is the same in Asia. A survey of 1023 families of children with disabilities discovered that 97% of the sample had received no help whatsoever (Miles, 1985a:2). Only 5% of the disabled in Indonesia have access to the nation's urban-based services (Johnson and Tjandrakusma, 1982; ILO, 1982). The number of blind persons in the Philippines is estimated at 850,000 and yet the only provision, four rehabilitation centres based in urban areas, can cater for only 100 persons annually (Berman and Sisler, 1984).

A comprehensive survey of 33 countries, representing half of the world's population, identified 14 million physically handicapped persons of which 1 in 6 needed some form of special equipment. However only 1% had any form of aid at all. The international picture is therefore bleak; indeed where 'help' is available it may be nothing more sophisticated than the wearing of amulets to ward away evil spirits (Ahmadullah, Islam

and Ali, 1981). The amulets symbolise the mechanistic approach adopted in attempting to meet the challenge, as Miles (1983) observes:

> the cries of the oppressed filter through as bloodless statistics ..... while the response trickles back as theoretical programmes (unpub).

1.4 Limitations of the Institutionally-Based model of rehabilitation (IBR)

The international strategy in health has been to create relatively sophisticated services staffed by highly qualified personnel with the hope of expanding them progressively as resources increase until the whole population is covered (Djukanovic and Mach, 1975:7). The reality has been very different. The services have become centred on urban areas accessible only to a small and privileged section of the community.

The situation regarding rehabilitation is even more serious. In light of the millions of persons in need, the prevailing IBR model of rehabilitation has come under severe criticism (O'Toole, 1989a). The undue concentration on an urban elite (Rehabilitation International, 1981:44), the adoption of unnecessarily high standards of training (Hindley-Smith, 1981; Helander, 1977), the narrowness of specialisations (Menon, 1984) and the isolation from normal life (Periquet, 1984) are some of the criticisms levelled at the IBR approach.

The limitations of the IBR model are also apparent in the West. Hammerman and Maikowski (1981) state:

> nowhere in the world are the necessary measures being instituted to reduce the gap between available services and existing and predictable needs (p.44).

WHO support this assessment finding:

> only a number of un-coordinated, piecemeal attempts at a solution..... action taken is superficial with no comprehensive policy on disability (WHO, 1976:5).

25% of Americans live in towns with a population of 2,500 or less. For the disabled in these areas there is obviously less opportunity to make use of the wide range of services found in the cities (Cook, Ferritor and Cooper, 1981). Greenwood (1985) estimates that only 15% of the disabled population in rural America get any professional help. He stated: 'there is no evidence of any impact of rehabilitation services on these rural disabled persons.' The situation may be no better in the cities; Klein (1978) estimates that only 2% of stroke patients in Los Angeles received comprehensive rehabilitation. A similar situation is evident in Britain, where Gloag (1982) reports:

> a vast amount of unmet need in rehabilitation (where) good services develop as a result of the enthusiasm of individuals rather than according to an overall strategy.

1.5 Low utilisation of IBR facilities

An apparently paradoxical picture emerges in LDCs where people turn their back on free health services and where there is a significant under-utilisation of the available resources (Jobert, 1985; Djukanovic and Mach, 1975:18).

A two year study of a village only a few miles from a sophisticated rehabilitation centre revealed that only 10% of people in need made use of the services despite the offer of free transportation (King and Morley, 1976 :55). The same

response was evident in a rural health camp in India (Agarwal and Goel, 1978). A survey of the physiotherapy facilities in a 120 mile radius in Nigeria revealed that only 53 children were receiving treatment (Enwemeka, 1981). Even when sophisticated services have been temporarily set up in the village to assist disabled children only a minority of the mothers took advantage (Hindley-Smith, 1981).

The same pattern of under-utilisation is evident in the West. A survey of 74 families with mentally handicapped children revealed that despite the array of services provided there appeared to be little reflection whether the services offered were what the persons actually wanted and needed (Humphreys, Lowe and Blunden, 1985).

The low utilisation is especially apparent in certain sections of the community as a result of dissonance between the cultural orientation, values and expectations of service providers and potential clients. Such a pattern is evident amongst rural persons in LDCs (Benyoussef and Christian, 1977), American-Indians, Chinese-Americans and other minority ethnic groups in America (Ederton, 1970), and the working classes and immigrant population in Britain (Cunningham and Jeffree, 1975). McConkey (1986) observes that the very persons in need of services are the least likely to seek out help. Some method therefore needs to be found to make the services relevant and accessible to rural and minority peoples.

For those who do use the IBR services, many leave dissatisfied (Heller, 1982; Lasker, 1981; Kroeger, 1983). Parents often remain confused concerning the precise objectives of the various therapists they encountered (Fox, 1974:3). Hospital visits are often unhelpful, characterised by long periods of waiting only to be faced by the perfunctory attitude of the doctor (Hewett, 1970; Carr, 1974). The literature is replete with examples of frustrations experienced by families dealing

with the 'helping professions', (Cunningham and Sloper, 1977; Ayer, 1984; Brock, 1976; Smith, Kushlick and Glossop, 1977).

A major reason for lack of progress in this field is the concentration on the IBR model of service delivery (WHO1976:23). The low efficiency of having so many persons working with the same family, the poor co-ordination of the various services and the competition amongst different sectors for scarce resources (WHO, 1976:24) has led to IBR being dismissed, in some quarters, as being:

> not very effective and often useless... their training objectives and their delivery system have...become obsolete (Helander, 1984:133).

1.6 The need for an appropriate model of services

One reason for the lack of progress is that the professional roles which are adopted are inappropriate to the needs of LDCs. Karey's (1985) comment that 'special education in Africa is profoundly European in origin, practice and prejudice, in spite of political independence and Africanisation', is relevant to much of the developing world. WHO must share some of the responsibility in helping to create an inappropriate model when they recommended that the rehabilitation team should consist of 21 different specialists (WHO, 1969).

Bolden's (1985) review of rehabilitation provision in the Caribbean notes that services are patterned on an inappropriate North American model, including intensive overseas training only to result in the therapist returning home with an expertise which is often too sophisticated to apply and which is unsupported by the technology to which they had grown accustomed. Bolden (1985) concludes:

> after existing for 50 years in the Caribbean region, rehabilitation services are barely touching the surface of the problem of children with special needs (p.2).

We have been seduced by the modernization mirage which has fostered the illusion that Western skills, knowledge and attitudes should be diffused to developing peoples (Arbab, 1984). The mirage is so vivid that many civil servants insist that Western style institutions are the solution and anything else is 'humiliatingly second-rate' (Moyes, 1981). In our blinkered desire to imitate the services offered by the West we have lost sight of the true magnitude of the problem. The justification for the focus is the need to 'maintain standards'. However to the 98% of families who are presently receiving no assistance the argument concerning 'standards' has no relevance. For them the question becomes, quite simply, will any significant service reach them during their lifetime (Mittler and Serpell, 1986).

1.7 Changed approach to the concept of development

The 1980's has witnessed a change in thought and action concerning development with a movement away from a top-down model of service delivery. Previously social service programmes for rural communities have been planned and implemented by bureaucratic institutions without the consultation and involvement of the intended consumers.

There is a growing realisation that if the subjects of development do not participate actively in the relationship with those who would promote the development process, change will be impossible. There is a significant gap between the potential and practice in the area of disability. One reason for the gap is that volition is a pre-requisite of action (Arbab, 1984). The active participation of the subjects of development at all phases of the development process is

essential. One of the basic questions now becomes how can we guide individuals who, for so long, have traditionally been led by others, to take charge of their own affairs. We need to move away from regarding rehabilitation as a product to be dispensed, to offering rehabilitation as a process in which the villagers are intimately involved (O'Toole, 1987).

1.8 Emergence of Community-Based Rehabilitation (CBR)

The 1969 meeting in Dublin of the International Society of Rehabilitation (now Rehabilitation International), voiced the first public misgivings concerning IBR (Hindley-Smith 1981). The experts noted the significant disparity which existed between needed services and available provision and acknowledged that the gap could not be closed by developing conventional services. Questions were asked concerning methods of providing the most essential assistance to large numbers of persons utilizing readily available resources. The need for an innovative delivery system was recognised and formalised by WHO in 1976 with the publications of A29/1NF. Doc. 1 which outlined a new policy for disability prevention and rehabilitation. WHO then adopted a resolution (Resolution WHA 29.68 1976) recommending the provision of essential services and training for the disabled through CBR as part of the 'Health For All' Campaign.

The emergence of the concept of Primary Health Care entailed the acceptance of two important principles which had been vigorously resisted earlier. Firstly, that it is more important to bring about even small improvements among the entire population than to provide the highest standard of care for a privileged few. And secondly, that non professionals, with limited training, could provide crucial services.

WHO provided the stimulus for incorporating rehabilitation into Primary Health Care with the publication of a Manual, Training the Disabled in the Community (Helander, Mendis and Nelson, 1980).

1.9 What is Community-Based Rehabilitation?

Rehabilitation can be defined as:

> including all measures aimed at reducing the impact of disabling and handicapping conditions and at enabling the disabled and handicapped to achieve social integration. Rehabilitation aims not only at training disabled and handicapped persons to adapt to their environment, but also at intervening in their immediate environment and society as a whole in order to facilitate their social integration (WHO, 1982:5).

Rehabilitation has traditionally been based on buildings, equipment and professionals. A sacred aura has developed 'such that persons in LDCs are led to believe that anything else is unacceptable' (Acton 1983:82). Previously the individual and the problem were lifted out of the social context in which they existed and attempts were made to impose a solution in a new context of the therapist's making.

Most disabled persons live in rural communities. Rehabilitation is therefore best done in that environment with the child's care givers as the primary training agents. The family therefore need to learn what to do to help and require a system of support and encouragement.

The goal of CBR is to demystify the rehabilitation process and give responsibility back to the individual, family and community (WHO, 1982:5). A Local Supervisor (LS) is recruited from the community and trained. The LS could be a health worker, teacher, social worker or volunteer. The LS shows a member of the family how to carry out the training programme.

CBR is based on simplified methods of rehabilitation which, in the WHO scheme, are described in a series of booklets. CBR should use existing organisations and infrastructure for the provision of services. Simple tasks are therefore delegated to auxiliaries or volunteers whose performance is supervised by an Intermediate Level Supervisor (ILS).

CBR should involve the community in planning, implementation and evaluation of the programme. Links are established with higher referral services to cope with more specialised needs. CBR is an attempt to generate an exponential increase in appropriate skills, distributed to where the needs are by utilising hitherto unexploited resources in the community.

1.10 WHO evaluation of CBR

WHO field-tested CBR in 9 countries and concluded unequivocally that 73% of their sample of 576 disabled persons 'improved with training' (WHO, 1982:4).

The lack of improvement in the remaining 27% was explained by: the training period being too short; the subjects too old; the disabilities too severe; the need for referrals; and the problems involved in finding and motivating a suitable trainer.

1.11 Need for an independent evaluation of CBR

A number of organisational and methodological problems concerning the field-trials have been noted (O'Toole,1988) and will be reviewed in Chapter 2. The inadequacies of the IBR model are clearly appreciated, however the danger is that an innovation is justified purely on a priori rather than empirical grounds (Wedell and Roberts, 1982). Campbell (1969) questions whether administrators may become so committed in advance to the efficacy of the reform that they cannot afford

honest evaluation. Evaluation results are often only used when the findings are favourable (Whiteside,1978:107). There is a tendency for fashions to develop which become slogans and which are adopted before their impact is fully evaluated (Buckley, 1981). The reason for their popularity can lie more with their energetic promotion rather than any inherent benefits of the programme.

The approach has been widely accepted by international organisations to such an extent that by 1984 CBR was adopted and co-sponsored by WHO, UNICEF, ILO, UNESCO, and UNHCR as part of their contribution towards the Decade of the Disabled. CBR was also supported by NGOs; Rehabilitation International, World Rehabilitation Fund, Red Cross, SIDA and NORAD (Krol, 1984:280). By 1984, 40,000 copies of the Manual had been produced and translated into 20 languages (Helander, 1984:2).

Miles, who has presented the most detailed critique of the approach to date is concerned that:

> a number of dedicated and hard working volunteers are being persuaded to work in a scheme which has a number of fundamental flaws (Miles, 1985b:4).

He stresses the need for an independent evaluation of CBR by someone familiar with the country and financially independent of WHO. A beginning has been made in the area of evaluation of CBR projects by Madizma, Matambo and Else (1985) in Zimbabwe, Berman and Sisler (1984) in the Philippines, Jaffar (1985) in Pakistan and AMREF (1987) in Kenya.

1.12 Summary

There is a danger that CBR has been presented as a panacea, one approach equally relevant to societies as different as St.Lucia and Pakistan. IBR alone cannot meet the needs of disabled persons whether in the West or the developing world, an evaluation of CBR is therefore necessary because of the very real potential of the approach.

There is a need to move away from uniformity myths and investigate for whom such a programme is meaningful; which children, which families, what types of disabilities; and to see which LSs are effective. A detailed evaluation is urgently needed to determine whether CBR can meet the needs of disabled persons in a developing country in an effective and inexpensive manner. This research project is offered as one contribution towards suggesting answers to some of these issues. More knowledge is also needed concerning the implementation process and the dynamics of innovation to help in the formulation of more meaningful programmes in the future.

CHAPTER 2 CBR: PROBLEMS AND POSSIBILITIES

PROBLEMS

2.1 Training the disabled : a real perceived need in LDCs?

The rationale for CBR is based on the supposed magnitude of the problem; the disabled 10 per cent of the world's population (WHO, 1982:3). However it is debatable whether any reliable surveys have been carried out in LDCs to ascertain the precise magnitude of the problem (Finnstam,1985). There is widespread reluctance to co-operate with such surveys (Husbands, 1985; ILO, 1982). Surveys in Botswana and Mexico were stopped because of the perceived futility of counting heads when no services were available (Sebina and Kgosidintsi, 1981; Hindley-Smith, 1981).

The pilot-studies of CBR report consistently lower figures; Jamaica 1.3% (Thorburn, 1983), Burma 1.5% (World Health, 1984), Pakistan 1.9% (Jaffar, 1985), St.Lucia 0.7% (Husbands, 1985) and, for the two projects in India; 2.2% (Ephraem,1984) and 1.19% (Menon, 1984). The available figures may therefore only be symbolic of the size and scale of the problem rather than anything even approaching accurate estimates (Mittler, 1984).

There may be a danger that, in quoting high incidence figures, international organisations are making the classical mistake in development of defining others needs for them. It is worth considering how many of the 10% would regard themselves as disabled or would be thought of as disabled by their families (Mittler, 1984). In one study in India by Prablm (quoted by Miles, 1985b:6) only 1 in 7 of the persons identified by the study as retarded were actually regarded by the community as being disabled. Serpell (1984) questions whether professionals may exaggerate the magnitude of the problem because of their vested interests. The label handicapped in a LDC context may be

better reserved for those for whom differences amount to a severe life problem.

Rehabilitation has a long history of professionals establishing services without adequately consulting consumers as to what would be of most benefit to them (Russel, 1983:61). In adopting CBR professionals may not be responding to a priority request from villagers in LDCs.

2.2 Is parental involvement a realistic goal?

The pendulum has swung from the 1950's when one could have overlooked the fact that parents existed (Wolfensberger, 1967), to the 1980's where parents are lauded with the title of the 'only true educators' (McConkey, 1986). The crucial role of the parents is now enshrined in legislation in Britain, where the Court Report states, 'we have found no better way to raise a child than reinforce the ability of their parents to do so', and in America, where PL 94-142 extends the right and the duty, of parents to assume the role of education decision-makers. Parents who were earlier dismissed as part of the problem are now regarded as part of the solution.

The rationale for parental involvement is however based on federal mandates, legislation and common sense rather than empirical data. Evidence for the effectiveness of such programmes is limited (Gardner, 1983; Halpern, 1984; Bricker and Casuso, 1980; Reader, 1984; Judson and Burden, 1980). In more than half of the studies reviewed by Burden (1978) no reference to evaluation was made at all.

i) Is the role practical? Overwork, poverty, severe social tensions and sheer exhaustion make parental involvement a difficult proposition in LDCs (Thorburn, 1983; Kohli, 1986; Miles, 1985b; Ogunkoya,1982). Amidst poverty the scarcest resource is time which is devoted to survival. In such

societies, 'there may be little or no surplus energy or compassion to spare for the weaker members of society' (Miles, 1981:17).

Severe practical limitations also exist in the West where such pressing concerns may well threaten the centrality of the child in the parents' lives, 'in such cases the handicapped child's progress may be the least of the parents' worries' (McConkey,1986:37). Cunningham and Jeffree (1975) in Britain and Bronfenbrenner (1976:250) in America, acknowledge the difficulty of attracting poorer parents to their early stimulation programmes.

The parents most in need may have neither the resources nor the psychological energy necessary to participate in an intervention project, for them only fundamental ecological intervention may be relevant (Bronfenbrenner, 1976:250). It may therefore be unrealistic to assume that it will always be possible for parents to adopt a teaching role with their children, moreover there may be a risk of imposing both practical and emotional burdens on the families by advocating such a role (Mittler and Mittler, 1983:21).

ii) Do parents welcome the role? Professionals may be guilty of having adopted a stereotyped model of parents who see their handicapped children as special responsibilities, and who are willing and eager to give special teaching and play sessions to the child (McConachie, 1983:125). The assumption is that parents would welcome higher involvement in the educational process, the reality however may be very different. When asked to rate the characteristics of an ideal pre-school programme parents identified parental involvement as the least important factor; what they valued most was competent teachers (Turnbull and Turnbull, 1982). Assumptions behind parent programmes may be based more on what professionals think parents ought to be

rather than on a universally held parental preference for involvement.

A second assumption is that parents would find the work rewarding. However the vivid interviews recorded by Fox (1974) present a very different picture. Parents seek relief from their children rather than greater involvement. At times the relief takes the extreme form of the parent wishing the child would die (Fox, 1974:28,32).

In promoting greater parental involvement the effects of the handicapped child on the family may be underestimated. An extensive literature exists to suggest, 'a handicapped child means a handicapped family' (Kew, 1975:157; Buckley, 1984). The characteristic response of; extreme emotional upset (Gath, 1977 ; Richards and McIntosh, 1973), extreme isolation (Dupont, 1980; Wilkin,1979), disbelief, denial and grief (Mackeith, 1973) and depression (Dorner,1975) have been regarded to be 'so common as to be almost universal' (Kew, 1975:35).

iii) Is there a danger of an 'Educational effect'? A problem exists whereby the child's performance on a test becomes an index of the mother's effectiveness as a parent (Sandow, 1984:19; Serpell,1986). The very scheme which was designed to help the parents could undermine the parents' confidence in their own ability to meet the child's needs. A long term dyadic relationship with a professional could create a sense of dependency by the parents (Gray and Wandersman, 1980; Copland and Decates, 1985). The goal of an effective home link should however be to support and develop parents' skills and to render the professional redundant rather than to make the professional an increasingly vital contributor to the successful development of the family.

Intervention programmes may become too highly child-focused and overlook the wider needs of the family as a whole. Portage Home Visitors have been advised not to get drawn into social , emotional or marital problems, as their expertise is in 'teaching, not social work, counselling or psychology' (Shearer and Shearer, 1974:27). However, for the disabled child to function effectively in a well integrated family unit, the needs of the family have to be systematically addressed.

The family has far wider needs than those of the handicapped child alone. In a survey of 113 families with handicapped children in Britain, over 25% had serious marital and psychological problems (Cameron, 1985). Parents repeatedly stress the need for contact withempathetic persons willing to listen (Fox, 1974; Tarran, 1981). Moreover, by focussing narrowly on product and outcomes the child and the family may fail to develop a genuine understanding of the processes involved and this may lead to 'education without understanding' (McConkey,1981).

iv) Does the task of teaching adversely affect the Mother's unique role? Encouraging a mother to behave like a teacher may destroy the very contribution which is most important for her to make and may add stress to a parent-child relationship which is already fragile (Raven, 1980; Sloper, Cunningham and Arnljotsdittir, 1983). Mothers are being pressured into adopting perceptions, expectations and behaviours which are psychologically damaging to themselves (Lillie, 1981).

Raven (1980) suggests that some of the gains from parental involvement may be illusory resulting in the parents feeling more in control of their own destiny than is realistic, thereby creating false perceptions and unrealistic expectations. If progress is not forthcoming they either reject the programme or devalue their own attempts. Either way a painful adjustment

must result. Parents may begin to feel the lack of progress by the child is their own responsibility (Buckley,1981).

An added problem in parent involvement projects is the danger of the programme pushing the parents further apart. The father's role in the life of his handicapped child has been observed to be limited (McConkey, 1986:58; Ayer, 1984; Madzima, Matambo and Else, 1985:8). By concentrating on the mother-child unit to the exclusion of other family members, the services may only serve to increase the father's isolation and accentuate the differentiation between parents regarding their respective roles (McConachie, 1982:152).

2.3 Is the involvement of the community a realistic proposition?

The community is given a pivotal role in the WHO scheme of CBR:

> the community must realise that the lives of its disabled members must be improved and that the community itself has the capacity to do it...the active participation of the community is the key to the success of CBR (Mendis and Nelson, 1983:22)

However the concept of the community is very vaguely defined as, 'a group of persons living in a certain area', (op cit p 22). Ahmed (1978) questions whether a deeper understanding of community as entailing a common perception of collective needs and a joint responsibility for decisions is relevant in LDCs. To mobilise previously uninvolved populations with no traditions of community participation and with no mechanism for community involvement is a daunting prospect.

Official mythologies of community participation portray communities as harmonious entities. In reality they are often

divided, stratified societies (Segall, 1983). The conglomeration of castes, factions and classes even within a small village prevent the formation of a concept of community (Jobert, 1985; MacCormack, 1983). WHO may well be unrealistic in its assessment of the extent to which care is shared within the family and regarding the potential support available in the community. In practice, for community we should read family, and for family we should read mothers (Cooke and Lawton, 1984).

In the West the disabled have been stereotyped as being dependent, isolated, depressed and emotionally unstable (Yuker, Block and Campbell, 1960; Altman, 1981). Such negative feelings are amplified in LDCs where the overwhelming impression, from the published literature, of the attitudes towards the disabled is very negative.

Disability is explained in terms of witchcraft (Walker, 1983; Odebiyi, 1983; Adhikari and Gudalefsky, 1981), or as a curse from the gods (Ogbue, 1983; Ojofeitimi and Oyefeso, 1980; Ahmadullah, Islam and Ali, 1981: 209). In a number of areas teaching the handicapped is forbidden (Enwemeka, 1981) and only brings shame on the family (Oyemade and Olugbile, 1981). Okunade (1981) observed that the attitudes of the more educated persons in their sample where even more negative than the uneducated persons. 87% of teachers in one study had hostile attitudes towards disabled persons (Elegbe, Ojofeitimi and Oyefeso, 1982). Miles (1982) believes these attitudes are a reflection of the austerity of daily life in the LDCs. When one considers such attitudes it is perhaps not surprising that community involvement in rehabilitation projects is often absent in LDCs (Ogunkoya, 1982; Thorburn, 1983).

Community participation has become a new catchword (Midley, 1986: vii). The challenging reality of translating such laudable principles into action is often not appreciated.

2.4 Is the PHC system a viable infrastructure for introducing CBR?

The rhetoric of CBR talks about adopting an inter-disciplinary framework; however WHO clearly anticipate CBR operating within a health system (WHO, 1982: 4; WHO, 1981:19; WHO, 1976:31; Mendis, 1981). The programme co-ordinators are envisaged coming from a PHC background (Mendis and Nelson, 1983:1) responsible to a health committee (op cit p 17). However there are a number of problems in attempting to graft the CBR system onto PHC.

i) Health is given a low priority in the villages: A survey of 20,000 persons in 22 Indian villages revealed that health was ranked eleventh in order of priority, far behind education, better markets and water (Chand and Soni, 1983:90). The same low priority was evident in another Indian village despite the fact that none of the under five population was regarded as healthy by visiting doctors (Sevagram,1983). The villagers simply feel no need for improved medical services (Arole, 1975).

A number of the effective PHC programmes were successful as a result of integrating health care into some other area of development more highly valued by the rural community. In Guatemala, Behrhorst(1975:41) focused on agriculture, literacy and family planning. Nugroho (1975:102) began with introducing irrigation in Indonesia and the Sevagram team were only effective once they organised a bank loan for the villagers in India (Sevagram,1983). If health is given a low priority, care for the disabled will be far lower.

ii) Lack of support for PHC projects: WHO assumes a genuine commitment to community-based services on the part of the governments. However it could be argued that, 'the greatest

obstacle to bringing effective health care to the masses are the doctors and the politicians' (Werner,1978:178).

The original concept of community-based services encompassed persons who organised themselves in a struggle for their rights. Governments have now adopted the term and use it, not for programmes which grow from the grassroots, but for projects which are planned and directed centrally and then implanted into poor areas for 'community participation'. Community involvement is now interpreted to mean the mobilisation of the people's money, labour and materials for some government controlled programme (Ratcliffe, 1983:85; Mukhopadhyay, 1983:134).

PHC requires a political commitment to an equitable society, a decentralisation of the decision-making process and a preferential allocation of resources to the poorest sections of society. Sickness, disease and malnutrition are symptoms of a deeper malaise stemming from social inequality, economic exploitation and political oppression (Morley, Rohde and Williams, 1983:322). PHC therefore challenges unjust political structures. It is not surprising therefore that most governments prefer to take their course of PHC in small doses (Segall and Williams,1983:301).

Despite the rhetoric the focus is still on curative care rather than on a broadly based attack on the real cause of poverty and disease. The very societies which pioneered the PHC movement are now reverting to Western-orientated, specialised, curative care, in Cuba (Werner,1983:29), China (Rohde, 1983:12) and Tanzania (Klovda,1983:58).

Doctors have been very reluctant to fulfil the crucial training, supervision and upgrading functions (Safilios-Rothschild, 1981:120; Kroeger and Franklin,1981). The health services are still regarded in a paternalistic manner; health

is something to be delivered to the masses (Segall, 1983).In India the reaction to the introduction of auxiliaries has been a mixture of contempt and alarm (Bose, 1983:44). Auxiliaries are regarded as competitors rather than partners in meeting the health needs (MacCormack,1983). The medical elite in Kenya have remained aloof from the PHC projects debating instead the location of the next hospital (Mburu,1980).

If the political and professional support has not been forthcoming with PHC there is less likelihood it will be given for CBR. Miles (1985a) can already hear the,'anguished reaction of the rehabilitation professionals who see their trade secrets being hawked in the market place'.

iii) Is PHC anything more than a second-class service? Reviews of PHC now see the scheme as loosing momentum; PHC has become stigmatised as the poor people's medical circuit (Jobert,1985; Skeet, 1984). PHC is promoted in words while urban, highly technical care is supported in deeds (Segall,1983). The dual standards are not lost on villagers who simply ignore the services (Djukanovic and Mach, 1975 :19). In Ethiopia (Kroeger, 1983), India (Banerji,1979), Nigeria (Murphy and Baba, 1981) and Guatemala (Annis, 1981) the local services were by-passed and the villagers approached the more distant facilities in the cities. Villagers now have urban-type expectations (Benyoussef and Wessen,1974; Muller,1983:197). Increasing levels of utilisation may therefore depend on improving the quality of care rather than on building more health posts or overcoming supposed cultural barriers.

iv) Can effective programmes progress beyond pilot programmes? Effective PHC programmes are either part of an international research project with significant manpower and financial investments (Walt and Vaughan,1981) or based on the charisma of key personnel (Djukanovic and Mach, 1975:96). The disillusionment of pilot projects which remain as pilot

projects is widespread (Newell, 1975:200). Jobert (1985) reviews more than 50 pilot programmes, none of which had effectively spread beyond the original setting. Vaughan (1980) questions whether local programmes can work on a larger scale. The prognosis for innovations is often poor once responsibility is transferred from the pioneers to local government administrators who approach the task with limited ability and enthusiasm.

The PHC system therefore has a number of limitations. There are moreover, added problems in attempting to graft CBR onto the PHC infrastructure.

v) PHC workers are overburdened: Mendis and Nelson (1983:19) list 10 major tasks PHC workers are expected to perform and then suggest that rehabilitation should be an added responsibility. Menon (1984) estimates that 25 per cent of the health workers' time would be spent on rehabilitation. The increase in PHC workers anticipated by WHO (Mendis and Nelson,1983:20) until a ratio of 1:1000is achieved has not materialised. The ratio in Sri Lanka is 1:3500 (Thangavelu, 1982) and in India, 1:5000 (Menon, 1984). St.Lucia and Jamaica recently lost 25% and 50% respectively of their Community Health Workers (Collymore,1985; Bryan,1985).

At the same time that WHO's Department of Rehabilitation was looking to PHC workers to carry the load for CBR, another WHO department envisaged using the same personnel to help the '13 to 18% of the population suffering from some form of mental disorder' (Sartorious and Graham ,1984; Climent et al 1980:235;WHO, 1984:6). Attempting to superimpose a rehabilitation model on a service system which is already overburdened is unrealistic.

vi) Calibre of persons to be trained: The practical problems of working with poorly educated persons has been noted (Serpell, 1986; Periquet, 1984:19 ; Ogunkoya, 1982; Jaffar, 1985:30). As a result of the limited training and the lack of any professional identity the families tended to regard the workers as one of them rather as someone qualified to work with disabled persons.

By contrast, the Portage system in the West uses Home Teachers with extensive professional experience (Revill and Blunden, 1980; Holland, 1981; Smith, Kushlick and Glossop, 1977). An initially effective Portage programme in Malaysia (Smith, 1986) run by nursing and teaching professionals, later proved ineffective when lesser-qualified personnel were used as the home visitors.

To the extent to which CBR fails to solve the problem of limited training to persons with little or no previous experience, CBR runs the risk of providing only superficial services and allowing mistakes in the application of poorly understood techniques to go uncorrected for long periods (Serpell,1986).

Nevertheless WHO envisage using volunteers as the home teachers (Mendis and Nelson, 1983:33). The volunteer ethic was however questioned in Nigeria (Ogunkoya, 1982) and Zambia (Nabuzoka, 1985) where the 'volunteers' demanded payment and the co-ordinators felt it to be a crucial need.

vii) A cheap approach? Thompson (1982:4) suggests that CBR has been adopted for the illusory reason of economics. The cost of IBR is presented by WHO to be approximately US$1000 per person, by contrast CBR is costed at $9.00 (Mendis and Nelson, 1983:12; Helander, 1984:135). However the calculations overlooked the costs of training, supervision and referral services (Miles, 1985b: 23). On the rare occasions where detailed costs are

given CBR does not appear to be an economic miracle. The cost per person is; Jamaica US$151 (McIntosh, 1980), Kenya $150 (Arnold, 1984), Malaysia $490 (Jaekle, 1986). Berman and Sisler (1984:52) estimate that CBR may be no more than 20% cheaper than IBR . If the rationale for embracing CBR is economics then the authorities will be alarmed by the considerable numbers of newly identified disabled persons who are found to be in need of more specialised IBR services (Hindley-Smith,1981; Thangavelu,1982).

2.5 WHO evaluation of CBR

i) Uncritical endorsement: WHO pilot-tested CBR in nine different countries and convened a meeting in Sri Lanka (WHO, 1982) to evaluate the results of the projects. WHO are explicit concerning the necessary conditions for the introduction of the pilot programmes including ; local and national support, effective PHC system, resource centre providing training, supervision and referral facilities, adequate communications and high literacy (WHO, 1982:8; Nelson, 1980). The field tests were therefore conducted under the best possible conditions. WHO concluded:

> CBR is an appropriate, feasible and economically viable approach to provide the most essential rehabilitation to the disabled in LDCs...the results are comparable to those of IBR.
> (WHO, 1982:4)

ii) Methodological problems: The evaluations were largely subjective; the St.Lucia report begins, 'these are purely subjective observations' (Mendis,1981). In none of the studies were any independent evaluations made.

Thorburn (1983) and Hindley-Smith (1981) report between 30 to 40% of the disabled persons solving their problems unaided. When WHO claim a success rate of 73% (WHO,1982:13), the success

may therefore be with persons not regarded as disabled by the community.

Despite the claim that rather strict rules were used to determine if an individual was improved or not (WHO, 1982:13), no specific criteria was given by which one could objectively assess improvements. Ephraem's (1984) evaluation offers no information beyond,

> the Manual was very good, the teaching was very effective and results were most encouraging.

Menon (1984) identified 40% of the sample as having 'definitely improved'; however the only four categories of assessment used did not even allow for the possibility of failure.

In a number of cases there were questionable correlations between local findings and public conclusions. A review of the Botswana project (Kgosidintsi,1983) was very critical of the approach:

> very little training has been done (p10)...75% of the Local Supervisors have not even started doing anything with CBR (p40)...no interest by Local Supervisors (p78).

Sebina and Kgosidintsi (1981) also report the work as being too demanding. However the conclusion offered by WHO is:

> in spite of some passing difficulties, the programme has been accepted as ideal for a developing country such as Botswana (WHO, 1982:9).

The results in Pakistan are very similar (Jaffar,1985), where:

> none of the Local Supervisors (LS) carried out even half of the activities they were supposed to do (p19) ...most LSs simply don't go to the homes (p29)...only 2% of persons benefited highly from the programme (p25) ...the majority of families were at best indifferent, and, at worst, positively hostile to the programme (p29).

Again, despite the apparent evidence, the official conclusion regarding the trial was :

> the evaluation carried out has proved that the programme was a successful one (UNICEF,1985).

Hindley-Smith (1981) offers more moderate claims for his project in Mexico. The figures he quotes are ; 30% solve their problems unaided, 40% are helped by CBR, 30% need more highly trained personnel or IBR facilities. However the results of the study quoted by WHO (1982:10) read; 70% of the problems could be solved by using CBR, 20% need special help from the intermediate level referral services and could then carry on their training at home, and 10% need the more highly specialised care provided by IBR. Hindley-Smith(1981) concludes:

> it is not being claimed that this level of services is as good as that available at the institutional level but that it is a good deal better than nothing.

The disparity between local findings and public conclusions needs to be appreciated in light of the fact that none of the evaluations were done independent of WHO. Miles' (1985a) analogy is therefore very appropriate:

> just as the child is about to remark on the absence of the Emperor's clothes, it dawns on him that he may not be asked to court again.

iii) Organisational problems: Whilst on the one hand there were a number of methodological problems with the WHO field-trials there were also several constraints which prevented them from being a fair test of the CBR approach.

WHO has provided a detailed guide for a 75 hour training for LSs (Mendis and Nelson, 1983). A number of the field trials however report a far less rigorous training programme (Serpell and Nabuzoka, 1985; Periquet,1984:23; Sebina and Kgosidintsi,

1981; WHO, 1982:9). In Kerala there were 2½ days of workshops spread out over 3 months 'so that the course did not interfere with the health workers daily routine work' (Nelson, 1980:5).

A number of the programmes also used an inappropriate organisation structure. In India (Ephraem,1984), CBR passes through 5 different hierarchies before the training ideas finally reached the disabled person. The very name of the project, 'Health for One Million', reflects the ambitious and disparate goals which included; family planning, education and inoculation campaigns. It is not surprising therefore that there was ,'very little time in the project for rehabilitation' (Ephraem, 1974:11). Menon (1984) reports the LS only making visits to the homes on a monthly basis. The Jamaica project came to a halt because of a polio outbreak (Thorburn,1983). Transportation and supervision problems plagued the trials in the Philippines (WHO,1982:11), St.Lucia (Collymore,1985) and Nigeria (WHO, 1982:11).

Moreover a lack of commitment to CBR is reflected in the Nigerian study where Ogunkoya (1982) admits 'to our amazement (that) the people in the area actually looked forward to our arrival'. It is therefore not surprising that a programme which began in January 1980 in 7 states with 44 LSs had withered to only one programme 6 months later (WHO, 1982:11).

It could therefore be argued that WHO have not given their own approach a fair trial. It would appear that we know more about the inadequacies of the service models than having prototypes of more suitable ones (McConkey,1986). There is however a more optimistic literature to review.

POSSIBILITIES

2.6 CBR : responding to a locally perceived need

Repeated visits have to be made to rural communities before parents admit to having disabled children. However,once parents see tangible help being offered to others in their position they will seek assistance (Rafiq and Jaffar, 1986). It is not difficult to appreciate the lack of interest in mothers to simply having their child counted by a researcher. The identification of disabled persons in a community cannot therefore be a static event. This may help to explain some of the apparently contradictory evidence reviewed earlier concerning the precise magnitude of the problem.

The effective programme in Zimbabwe (Mariga, 1986)grew out of a recognition that the existing services were not meeting the present needs. The rural outreach programme was organised by Zimcare Trust who were responsible for the education and training of the mentally handicapped persons in the country. Their 15 centres, employing 300 staff were catering for only 900 persons. The National Disability Survey estimated there to be 27,000 mentally handicapped persons in Zimbabwe (Madzima, Matambo and Else, 1985). Zimcare recognized that more centres were not the solution and therefore began an outreach programme to help disabled persons in their own communities. Now, with demonstrable success, the programme is being expanded to other outlying areas (Mariga and McConkey, 1986). In Kenya the Family Support Service grew out of a local self-help group who ran a small school in the capital and who realised the need to move out into the rural communities to meet the needs of disabled persons in rural communities (Arnold, 1986). The programme is now being used as a training base. Project Projimo in Mexico (Werner, 1986) grew out of a local realisation by the Village Health Workers that the needs of the disabled in the rural

areas were not being met . In these cases the outreach programmes responded to locally perceived needs.

2.7 Parental Involvement: theory and practice

i) Rationale for parental involvement: Those with the highest motivation for helping the children are the parents themselves. Parents generally care for their children and want them to attain their maximum potential (Shearer and Shearer, 1974). Of the total time available for teaching the handicapped child only a limited amount is spent in school, and it is argued that the home plays a greater influence on the child's educational achievement than the school (Mittler, Mittler and McConachie, 1985:13). When the child is taught in her home and reinforced by her parents it is more likely that learned behaviour will generalise and be maintained, a major problem for handicapped children (Stokes and Baer, 1977).

Working in the home affords direct and constant access to the full range of the child's behaviour as it occurs naturally (Shearer and Shearer, 1975). Many aspects of the behaviour could not be targeted for modification in the classroom. Increasing the parent's ability to manage and train their own children lessens the risk of poor parent-child relationships and produces psychological gains in the parent which will benefit younger and subsequent children (Cunningham and Jeffree, 1971; Barna et al, 1980; Gray and Wandersman,1980). In pursuit of the philosophy of normalisation (Wolfensberger, 1967) it is logical that the intervention be offered in what is obviously the least restrictive environment, the home.

ii) What it means to have a handicapped child: There are many parents who would not be able to relate to the pessimistic literature reviewed earlier on the impact of a handicapped child on the family. Roith (1963) suggests the stereotypes of guilt, shame and depression are simply copied from one report

to the next. The literature has also been challenged on methodological grounds (Voysey, 1975:26 ; McConachie, 1982:161), using unrepresentative samples (Furnham and Pendred, 1983).

The literature tells us nothing about what it is like to have a disabled child in the family, but a good deal about other people's ideas of what it ought to be like (Voysey, 1975:2). Anything parents have said or done has been used in evidence against them. When Carr (1974) talks about 'pathogenic attachment' and Schaffer (1964) dismisses the 'too cohesive family' it seems that genuine love and concern cannot be admitted. If parents make allowances they are 'over-protective',if they attempt to minimise the disability they are 'failing to accept the situation'. Too often the researcher has fallen back on their psychological ancestry to analyse the data (Wolfensberger, 1967:345).

By contrast, Hewett (1970:194) states that most families manage to adapt to having a handicapped child, indeed in some cases the birth of a handicapped child brings the whole family closer together (Voysey,1975:143; Hare et al,1966; Burton,1975; Lansdown,1981). The disparity in the literature is simply a reflection of the variability which exists between parents with different degrees of capability, time and energy in dealing with their children (Turnbull and Turnbull, 1982).

iii) Do parents want assistance? Werner (1985) acknowledges that for practical reasons of unemployment, poverty or ingrained attitudes, there are families where involvement is unrealistic, however for each of these cases:

> there are at least six who are not only willing but eager to assume responsibility in this area provided they can access adequate information and guidance (op cit p60).

Jaekle (1986) argues that parents do want to help, however they do not know how to proceed. Parents invariably emphasise the need for practical information, support and advice (Hewett,1970; Hannan,1975; Fox,1974).

Satisfying parents' emotional needs is a vital first step in helping the parents come to terms with the way they feel. Arnold (1986) stresses the need for parents to have someone to talk with, to help overcome the feelings of shame and guilt. The need for emotional support is emphasised by Cunningham (1975:185). What parents valued most was knowing there was someone to whom they could turn at any time. Parents do want assistance, however their major need is in the affective domain. Highly child-focused, cognitively-oriented programmes may not be responding to the parent's needs and may lead to the 'educational effect' reviewed earlier.

2.8 Community involvement: hopeful signs

The pervading negative attitude towards disabled persons in LDCs has already been discussed, however Miles (1983:13) emphasises that there are few well controlled studies of attitudes in LDCs, much of the literature is impressionistic and anecdotal.

Community attitudes vary a good deal more than the reports would suggest. They vary not only across societies but also within them and between adjacent neighbourhoods (Seed,1980). Dexter (1964:42) suggests there is less prejudice against the disabled in LDCs. The handicapped are fully accepted in parts of Kenya and Polynesia (Ederton,1970:528). In Egypt, mentally handicapped persons are believed to possess a 'saintly touch', (Ammar,1954:288). Some North African groups regard families with handicapped children as 'especially favoured', the logic being that God would only select devoted, loving families to

receive a handicapped child. Whilst the above could be criticised as being impressionistic, anecdotal and dated, it does at least help to balance the uniformly negative picture presented earlier.

The attitudes may therefore be a little more enlightened than was suggested earlier. Moreover there are examples in LDCs where the community has been deeply involved in rehabilitation projects. Kgosana (1984) reports a high degree of community involvement in Sri Lanka where a committee, composed of village elders met monthly to monitor the project. The handicapped persons became the shared responsibility of the community (Johnson and Tjandrakusma,1982).

The very name of the project in Mexico, 'Projimo', means good friend or neighbour in Spanish. The leaders of the community were interviewed and all were found to be involved in some way with the project (Villegas,1985:67). In Burma (WHO,1982:10) and the Phillipines (Valdez,1984) a high degree of local involvement in the programme was achieved through a process of effective dialogue with the barangay leaders and extensive propaganda.

2.9 Work within what infrastructure?

CBR may only be viable on a nation-wide basis if it can be incorporated into an existing government machinery which already has an operational rural service (Arnold,1986; Jaekle,1986)

The effective outreach programme in Zimbabwe (Mariga,1986) was based on a partnership with agencies already working in rural areas; Red Cross, Cheshire Home and the Ministry of Health. An effective infrastructure already existed and was well

accepted in rural communities, thereby allowing the new programme to be speedily implemented and effectively integrated with existing community work. The method of introduction may therefore vary from one location to another; the innovation needs to be adapted to the respective strengths of each community.

2.10 Can CBR be anything more than a second-class service?

As significant expansion of IBR services is impractical, it is left to CBR to see if the new model can effectively meet the challenge.

The need for on-going training and supervision is given high importance in the Portage scheme:

> whatever method of staff training is adopted, the regular monitoring and supervision of staff plays a vital role in maintaining the quality of the service given (Revill and Blunden,1980:16).

The same detailed attention to training was a characteristic of some of the effective early intervention programmes. The programmes in Malaysia (Jaekle,1986), Jamaica (Thorburn,1983), the Phillipines (Berman and Sisler,1984) and Peru (Jesien,Aliaga and Llanos,1979) all featured several weeks of intensive training before the LSs began work with the families.

In the final analysis a programme succeeds or fails as a result of the calibre of the staff available. The qualities needed to become effective local supervisors and the precise training and supervision requirements need to be investigated.

2.11 Summary

The literature is therefore divided. Does CBR work? If so how does it work? For whom is the approach most effective and how could CBR work better? What are the potential problems in adopting a CBR approach? What type of parents, with what type of children benefit from which parts of the programme? These questions cannot be answered by examining the presently available literature.

Whatever the precise percentage of disabled persons in the population it is clear that the magnitude of the problem is far greater than can be met by IBR alone. CBR has been presented as an alternative. Unfortunately WHO have presented CBR as a panacea. Some of the limitations and assumptions underlying the WHO scheme have been examined and examples of more effective practice has been reviewed. A major reason for the poverty of the literature in this area is the lack of suitable methods of evaluating whether or not a programme is in fact effective. Table 2.1 outlines the questions which this study plans to examine and Chapter 3 suggests an appropriate methodology for formulating answers to these questions.

Table 2.1 Research Questions

1. **Is the rehabilitation of the disabled a locally perceived need in the community?**

   * what is the magnitude of the problem of disability?
   * how adequate/appropriate is the available provision?

2. **Is the concept of simplified rehabilitation a viable response?**

   * how is CBR viewed by parents and professionals?
   * can rehabilitation be simplified without being reduced to a second-class service?
   * does an infrastructure exist which could accommodate CBR?
   * is the training of auxiliaries/volunteers a viable way to introduce rehabilitation?
   * are the auxiliaries/volunteers motivated/capable ?
   * are the auxiliaries/volunteers accepted by mothers?
   * what sort of training is necessary?
   * what qualities are necessary to be effective as a local supervisor?

3. **Is the promotion of parental involvement culturally appropriate in a LDC context?**

   * do parents accept the role?
   * are parents effective in the role ?
   * what gains are observed in the children?
   * do parent's attitudes to their disabled child change as a result of the programme ?
   * are there any negative effects of the programme?

4. **Is community involvement a realistic expectation ?**

* how can the community become meaningfully involved?
* what is the process by which the community becomes involved?
* do attitudes in the community change as a result of the programme?

5. **Does CBR establish meaningful links with IBR services?**

* is a two-way channel of referral established between IBR and CBR?
* how do rehabilitation professionals react to the programme?

6. **Is the CBR model a realistic way of assisting high numbers in need?**

* how many persons could be helped with these services?
* how many children could each LS work with?
* is the programme a realistic way of closing the gap between the need and available services?

7. **Is the programme cost-effective?**

* in view of the resources used are the gains meaningful?
* is the programme financed at a level which could be realistically maintained?

8. **What are the essential features of introducing an effective innovation?**

   * what planning is required for an effective innovation?
   * what method of training/supervision is effective?
   * how crucial is the role played by the co-ordinator?

9. **In what ways does the WHO scheme need to be supplemented?**

   * how has the WHO scheme been adapted in this research programme and why?

CHAPTER 3: IN SEARCH OF AN APPROPRIATE METHODOLOGY

3.1 Questions to be asked

Evaluation is the process which attempts to determine, as systematically as possible, the relevance, effectiveness and impact of activities in the light of their objectives. The objectives of CBR, as defined by WHO, include the following;

> the adoption of a simplified form of rehabilitation,
> training of auxiliaries and volunteers from the community,
> mobilisation of resources within the family,
> and the utilisation of an existing infrastructure,
> (Mendis and Nelson,1983:33).

This research investigates how these principles can be put into operation and then attempts to assess the relevance and effectiveness of the various aspects of the programme.

3.2 Poverty of available literature in the area of parental involvement

The definition for evaluation can be easily stated, reliable answers are considerably more elusive, as Vaughan (1984:60) notes:

> the need for evaluation is universally agreed, in practice (however) it is rarely carried out ...the major reason is the difficulty of carrying out a good evaluation.

In 7 out of the 13 parental involvement programmes reviewed by Levitt and Cohen (1975) no attempt was made to evaluate the effectiveness of the programme. Stedman (1971) observes that the programmes are often inadequately designed thereby making evaluation and replication impossible. Gray and Wandersman (1980) note that early intervention does not have a uniform impact on all participants, some improve, some drop out, some

stay the same and some may even be harmed. The variance in results could well depend on economic and social factors, information that is routinely collected but rarely analysed.

There is presently little reliable evidence for predicting which families are likely to benefit from the intervention programme (Baker,1984). Simeonsson, Cooper and Scheiner (1982) review 27 early intervention studies for biologically impaired children. Objective statistical support for the effectiveness of the programmes was offered in less than half the studies, nevertheless 93% of the programmes claimed 'success'.

3.3 'Unscientific data'

A frequent criticism of the data is that the researchers failed to meet the canons of science in the studies:

i) Discrete treatment: The traditional experimental approach examines a single, identifiable and measurable treatment and assumes that once introduced treatment remains constant and unchanging. In reality treatment is dynamic, complex and multi-dimensional. Treatment changes as the researcher learns what is effective; different families therefore experience different treatments in a non-systematic fashion.

ii) Adequate controls: The logic of experimental and statistical inference demand conditions which are difficult, if not impossible, to meet in human studies (Levine,1974). It is difficult enough to match handicapped children on apparently clearly defined areas, such as physical factors, let alone the vast array of other important variables such as degree of handicap or intra-family differences (Sandow,1979). To be able to generalise to the wider population one needs to use a random sample. However, the parents often constitute a self-selected

group, highly motivated to succeed (Baker,1984; Ferry,1981; Stedman,1971).

iii) Replication: The programmes are often not sufficiently detailed to understand what the researcher did, making it difficult to replicate or isolate the variables which were related to the treatment (Stedman,1971; Burden,1979). A major intervention programme has many components, ascribing effectiveness to any one variable is a tenuous process.

iv) Follow-up: Many of the studies do not involve the families in the intervention for a sufficient amount of time to allow for long term change or an adequate test of the intervention programme (Ferry,1981; Stedman,1971).

3.4 Limitations of the 'scientific' method

The label 'research' has become synonymous with employing the 'scientific method', with technical excellence being the accepted criteria for evaluation (Cronbach,1982:9). The strong endorsement of conventional methods of evaluation has blocked the search for valid alternatives (Levine,1974:661). The search for methodological purity has sometimes over-looked the substance of the problem to which the methods are applied. Evaluation has become a straight-jacket in measuring performance where, 'the tools have now become our masters' (Azrin,1977:140)

There are however growing signs that the dominant paradigm is no longer all-persuasive (Patton,1980). Cronbach (1975:123), previously a major supporter of the scientific approach, now advocates the appropriateness and usefulness of qualitative methods. Assessing the impact of a fixed plan is not necessarily the best use of evaluation, improving the programme is a higher goal and one to which formal quantitative

comparisons usually contribute very little. The need to study the subject in their individual and total context has been stressed (Schindele,1985:3: Magoon,1977:686).

The adoption of qualitative methods of evaluations is not only because of the limitations of the quantitative approach but because topics for enquiry need to be matched with appropriate forms of evaluation. The research topic must lead the method and not vice versa (Hegarty,1985:109). Too often topics are defined for enquiry in terms of what can be handled by quantitative methods, however human action and behaviour can only be understood in terms of how the participants perceive and understand significant events.

The complexity of the research topic necessitates a battery of measures to balance the strengths and weaknesses of different approaches in assessing which aspects of the intervention can facilitate which areas of competence. Research is needed not only to describe facts but to strive to understand subjective definitions and complex relationships, discovering meaning is as important as evaluating quantitative facts. Understanding behaviour from the individual's own frame of reference becomes a major goal, an area which demands a multi-disciplinary approach but for which too few bridges between disciplines have been built.

3.5 Need broader concept of evaluation

Werner's (1986:44) evaluation of Project Projimo, a rural rehabilitation programme in Mexico, illustrates some of the problems inherent in the evaluation process. 60% of the clients were judged to have clearly benefited from the programme, however many of the remaining 40% had also progressed but in more subtle ways. The danger is that evaluation focuses only on what can be readily measured and intangible feelings such as,

increased hope, improved relationships with others, and self-satisfaction are overlooked.

Success cannot be judged solely in terms of the child's performance on some measurable scale (Bricker and Casuso,1980; Dessent,1984; Cunningham,1983). The child's progress needs to be viewed from the context of their particular disability. The value of CBR may reside as much in the opportunity provided for a supportive, caring and befriending relationship as in developmental gains in the child.

A major obstacle to meaningful evaluation has been the lack of measurement tools for social, affective and interpersonal change (Stedman,1971). The need for more subtle measures of assessment has been recognised by Levine (1974:667);

> we have accepted uncritically the notion, "that which exists, exists in quantity and can be measured" and the insidious corollary that if the concept cannot be reduced to precise quantitative treatment, we are dealing with unscientific material.

We need to rethink the concept of success and failure and investigate better methods for assessing the quality of life of the child and the family. Priorities have often been set in terms of what can be easily measured, by contrast, Cronbach(1982:xvi) advocates investigating what is important whether or not the questions fit conventional paradigms.

The goal of qualitative evaluation is to examine the process of the innovation and not simply focus on the products, the objective is not to predict but to understand, the researcher can;

> give up the burden of producing unassailable certainties and concentrate on the more immediate task of providing information to decision-makers (Patton 1978:283).

There is a danger at present that the roles of scientist and practitioner are regarded as mutually exclusive (Salkovkis, 1984:376) Most clinicians are simply not doing research (Watts, 1984:41; Hayes, 1981). Traditional research tools are regarded

as incompatible with clinical realities. Scientists, in their search for precise cause and effect relationships, often dismiss naturalistic research as unacceptable. In turn, practitioners regard the assumed elegance of science and group comparison designs to be irrelevant to their needs and unable to deal with the complexity of the problems they encounter. N=1 designs have been offered as one method of bridging the roles of the researcher and the practitioner (Kratochwill, 1978).

Complex questions in evaluation however, need to be tackled with both quantitative and qualitative methods, the findings of one complementing the other (Wedell, 1985:2). The polarisation between the two approaches has been misleading and unhelpful. Discovering meaning now becomes as important as evaluating quantitative facts (Schindele, 1985). The N=1 data will therefore be complemented by a number of other quantitative and qualitative measures.

3.6 Multiple Baseline Design

i) Rationale: The Single Case Research Design has been suggested as one way of bridging the demands of the roles of scientist and practioner. In an N = 1 design the subject becomes his own control. Repeated measurements of behaviour are made in, at least two experimental conditions, baseline (A) and treatment (B). If a measurable change in behaviour is seen after introducing treatment, the probability exists that the intervention is responsible for the change. the search for an appropriate design is not however a simple matter. We are informed by Herzen and Barlow (1976:170) that the most appealing design, the AB design, 'should only be used as a last resort'. The uncontrolled factors in the simple AB design cause difficulties in making reliable cause - effect conclusions. The major problem is the lack of information on the natural course of the behaviour in the absence of any

intervention,one cannot rule out the influence of historical or maturational variables. However designs with higher potential for internal validity often present severe constraints on the practioner by advocating the use of extended baselines, reversals and withdrawals. The very aspects which ensure internal validity reduce their applicability in the service setting.

The AB design is therefore susceptible to a number of threats to internal and external validity, the Multiple Baseline Design (MBD) attempts to overcome some of these threats.

ii) Repeated measurements: The design relies on repeated observations of performance over time, the more frequently the measures are taken the greater the degree of precision. The effect of intervention on performance over time can be analysed, the approach therefore moves beyond only examining final outcomes to investigating the pattern of change over time.

iii) Baseline: Repeated measurements are made of the natural level of the target behaviour, this becomes a standard against which the effectiveness of the treatment can be judged. The baseline data serves as the basis for predicting the level of performance for the immediate future if the treatment is not provided. For the prediction to be reliable the baseline should be stable or in a negative direction thereby providing a clear contrast between the conditions.

iv) Multiple Baseline Design across subject: Treatment is sequentially applied across several subjects eg S1, S2, S3. Once baseline behaviour is stable for S1, treatment is introduced for S1 while continuing to monitor baseline

behaviour for S2 and S3. Once a certain criteria is reached for S1, treatment is introduced for S2 while continuing to monitor the target behaviour of the other Ss. The systematic and sequential introduction of the independent variable continues until all the Ss have been given the experimental treatment. The Ss should be functionally independent of one another so that the baseline will remain stable until the intervention is sequentially applied to each S. The Ss should however be sufficiently comparable that the independent variable will be able to influence each in turn.

The effect of the intervention is demonstrated when a change in each S's performance is obtained as a result of the introduction of the treatment. The stability of the behaviour in baseline phases and the magnitude and rapidity of change once the intervention is applied help to determine the ease with which inferences can be drawn concerning the role of the intervention. The effect of the treatment can be seen when changes are observed in the target behaviour when and only when the treatment is implemented at different times with each of several subjects.

v) Multiple Baseline Design across behaviours: Three comparable yet functionally independent behaviours are selected for each subject. Each target behaviour is measured concurrently and continuously under the same environmental conditions until a stable baseline trend and level is established. Treatment is then applied to one of the behaviours while the other two behaviours are monitored. Once a criterion is achieved on the first behaviour, the treatment is then introduced to the second behaviour and then the third. There is therefore a systematic and sequential application of the independent variable across behaviours until all three target behaviours have been exposed to the same intervention. A clear demonstration of B requires that behaviour changes only when

treatment is introduced, if improving one behaviour also improves other behaviours prior to exposing the latter to treatment, the cause-effect relationship between treatment and improvement would be unclear.

The validity of the effect could be increased by ensuring the phases are long enough to demonstrate stability, the behavioural changes could then be judged to be the result of each criterion shift and not historical, maturational or measurement variables. The more immediate the therapeutic change after the introduction of treatment, the stronger the case for saying treatment led to improvement. If the effects are strong and seen in the majority of the children this consistency would imply a generality of findings.

vi) Problems of Multiple Baseline Design: The method necessitates a minimum of three subjects, or three behaviours, each independent of the other and yet each responsive to the same independent variable. If behaviour covariation occurs within baselines not yet exposed to treatment there would be an ambiguous demonstration of effects and experimental control would be weakened. Ideally the targeted behaviours should be functionally independent of one another so that baseline data will remain stable until the intervention is sequentially applied to each. However with social behaviours the prediction of independence is difficult, eg in teaching a child to walk, social interaction with others is improved thereby producing a covariation across targeted behaviours. As the use of a MBD across behaviours alone would risk generalisation and loss of experimental control the present study will use a MBD across behaviour and across subjects.

In a MBD, behaviour needs to be observed for long enough to establish a stable baseline and to counteract the potential threats of history, maturation, and reactivity of observation.

Repeated testing without training can however become a meaningless exercise to parents (Jacobi, 1977, Strain and Shores, 1979). A trade-off is therefore necessary between establishing a stable baseline and risking the danger of subjecting the parents to a frustrating experience (Cuvo, 1979). A minimum of three data points in baseline can be accepted if there is no great fluctuation between the three points and if the anticipated effects are significant (Herzen and Barlow, 1976; Barlow, Hayes and Nelson, 1984:172). Azrin (1977) recommends using the shortest possible baseline sufficient to establish the trend in behaviour. Any fluctuations however will necessitate that more responses are recorded in order to identify possible patterns in baseline performance.

The N = 1 approach was therefore adopted as a compromise between the rigours of a traditional experimental approach and the practical demands of an action project. The classic experimental design did not lend itself to the clinical setting of the present research where the crucial independent variables were difficult to hold constant. The concept of: random assignment to treatment, homogenous treatment within groups and equivalence between repeated measures were impractical in the project setting. The lower generalisation of the N = 1 approach was offset by offering a more relevant model of assessment. Moreover, it was hoped that the insights gained by the N =1 method would be complemented by qualitative methods.

3.7 Qualitative Analysis

CBR may have a fixed plan, however the interpretation by staff and the involvement of clients determines the outcome. In asking if a play 'works', one must go beyond the script to analyse how the roles are portrayed. The evaluation needs to

focus on the 'process' of the innovation rather than simply examining 'results'. It is not enough to ask, 'does CBR work?', one needs an understanding of what happens on the programme.

An analysis of the strengths and weaknesses of the innovation, the way in which the programme is perceived by the participants, the quality of the family's experience, the constraints under which the programme operates, needs detailed, holistic descriptions. The programme needs to be analysed from the perspective of the participants, examining their observations and interpretations. The research is judged by its perceived relevance to the clients, the researcher needs to enter into a dialogue with those most closely concerned with the outcome of the research thereby understanding their needs, their problems and the approaches they have found helpful and unhelpful.

A series of case-studies will attempt to respond to some of these issues and offer some indication of the potential of the approach when effectively implemented. As Cronbach (1982:70) notes, 'it seems almost perverse to judge the treatment by its average end result'.

The case studies will be explicit regarding: setting, organisational features, procedures adopted etc. The clearer the description the easier it is to defend the internal validity of a conclusion and the greater the confidence that another researcher would reach the same conclusion. There are no reliable quantitative measures for many of these areas, the task therefore is to present the data in a way that allows others to form their own judgments (Cronbach, 1982:108). The material is collected as open-ended narrative without attempting to fit the experience into standardised categories. The attempt is to capture what persons have to say in their own words. The open-endedness allows the reader to examine the world as seen by the participant.

The benefits of the programme are described rather than being reduced to a quantity. Observations are opportunistic and responsive, not pre-structured. The major goal is to unravel what is seen rather than attempting to manipulate and control. The hope is to see the programme through the eyes of its developers and clients, revealed through a series of interviews, observations and questionnaires.

For research to be realistic and helpful to practioners and decision-makers an attempt needs to be made to analyse the whole complexity of the procedure, analysing both successes and failures and investigating which elements of the programme are crucial to success. The goal is not to provide 'truth' but offer a perspective. However ways of validating and verifying that perspective need to be examined. Steps need to be taken to ensure the reliability and validity of the findings.

3.8 Threats to Internal Validity

Is the intervention and only the intervention responsible for the change in behaviour? Is it possible to rule out other explanations for the results? Threats to internal validity exist in both the quantitative and qualitative approaches. The respective threats to internal validity will be considered and suggestions for overcoming the problem in this study will be offered.

i) History: A threat to the validity of AB designs is that of history, events extraneous to the independent variable which occur during the experiment and which may influence the outcome. In the MBD the actual time of the phase change is arbitrarily altered thereby reducing the threat of correlated extraneous events. If changes are observed only when treatment is introduced, then treatment and not some extraneous event

would appear to be responsible for the change. Repeated measurement of the natural level of the target behaviour is a standard against which the effectiveness of the programme could be judged.

ii) Maturation: Hindley-Smith (1981) and Thorburn (1983) note that 30% of their sample of disabled persons improved significantly without the benefit of any formal intervention. Change therefore occurs spontaneously in the subjects over time. The MBD helps to assess whether it is the intervention, and only the intervention, which is responsible for the change in behaviour and helps to rule out other possible explanations of the results. The MBD replicates the effects seen in the AB design but with different lengths of baseline for each replication thereby controlling for the possible confounding effect of maturation. If marked treatment effects are observed, history and maturation are unlikely explanations. The more immediately behaviour changes after treatment is introduced, the stronger the case for saying treatment produced the change.

iii) Prognosis: If there has been a long history with no real progress and change begins to appear once treatment is introduced one might suggest that treatment was responsible for the improvement. Moreover a knowledge of the probable prognosis of a condition may increase the inferences which could be drawn regarding the impact of treatment and might help rule out the possible explanations of history and maturation.

iv) Testing: The effect of testing is another potential threat to internal validity. Stedman (1971) observes that continual assessment, in itself, can have significant effects on outcome measures. The problem is increased when the same test is administered repeatedly or where the knowledge of a previous score can influence the assessor's judgement. A further problem

in this area is statistical regression where 'improvement' is simply an artifact of the tendency of scores at the extremes to revert towards the mean levels upon repeated testing.

However in the MBD, repeated testing becomes part of the whole exercise for all the children, the problem of testing is therefore overcome by on-going assessment. Problems associated with testing are not likely to influence the pattern of data over a high number of occasions and the fact that a condition is known to be stable make change due to testing an implausible explanation. Moreover if the effects seen in the first of a series of a MBD are because of testing, the same should be seen in other series if they are exposed to the same assessments.

If the case study includes continual assessment on several occasions some of the threats to internal validity related to assessment can be ruled out. When continual assessment is used changes due to testing or instrumentation would have been evident before treatment began. Moreover regression to the mean, a special problem when assessment is conducted at only two points of time, is eliminated. Repeated assessments allow an investigation of emerging patterns in the data.

v) Instrumentation: Any change which takes place in the measuring instrument or assessment procedure over time also constitutes a threat to internal validity. Such changes could result from the use of human observers whose judgement may vary over time. The individual may become fatigued, bored or more skilled at testing as the programme continues.

Before the programme begins a series of training sessions should be conducted separately for internal and external assessors to ensure agreement in the use of the assessment device. The assessment code needs to be used in a consistent manner throughout the study, at periodic intervals the internal

and external assessors will recalibrate their assessments through on-going training sessions. This would help overcome the problem of 'observer drift', the tendency to change the interpretations over time.

Inaccuracy is also caused by ambiguities in the dependent measures. The assessment instrument needs therefore to include items which are as objective as possible and attempts also need to be made to standardise the assessment procedure.

vi) Selection bias: The validity of the data could be affected by subject attrition, it is essential therefore that all the cases attempted are reported and analysed and not only those showing the desired effect. In the research all cases are accepted no matter how long lasting or severe the problem. An analysis of those who fail to complete the training could be instructive in the development of treatment alternatives for non-responsive clients. Client and situational differences which relate to the impact of treatment could be investigated. If the study could identify the boundary conditions of an effect, or conditions which maximise the impact, it would perhaps provide useful guidance for others. Both successes and failures need to be reported without assuming either in advance. The researcher needs to actively seek out negative instances and disconfirming evidence for emerging constructs which support alternative explanations.

vii) Researcher's predisposition: One's own predisposition and bias needs to be made explicit to help decision-makers judge for themselves the extent to which some subtle bias on the researcher's part has influenced the study. The researcher has worked for several years in an applied field with disabled persons in developing countries. The limitations of the prevailing IBR model to respond to this challenge have become

very apparent, at the same time it is felt that CBR has been offered by WHO as a panacea, as one approach equally meaningful to disabled persons from all backgrounds and all cultures. The present research is an attempt to guage the potential and limitations of the approach in one Third World context. The rhetoric of CBR is persuasive, however the magnitude of the task to be dealt with is very considerable. The researcher hopes and believes that an open-mind has been maintained concerning the potential of the approach.

3.9 Threats to External Validity

A major objection to N=1 designs is that the results are not generalisable to persons other than those included in the design. It needs to be investigated how far the results can generalise beyond the specific instances of the studies to other clients, families and settings.

A clear and detailed outline of the programme is essential to allow replications. Ideally the methods would be so clear that other researchers could use the report as an operating manual by which to replicate the study.

The generalizability of our knowledge depends on many systematic replications of effects across a number of clients and settings. N=1 depends on the principle of unlikely coincidences, as the number of coincidental effects increases, our confidence in the reality of the effects grows. Each replication should vary a key factor e.g. type of disability, experience of LS, support of father etc.,in an attempt to identify possible exceptions, if few exceptions are found, a wide generalizability of findings is established. If the effects are seen in a number of replications where extraneous events are inevitably varied across subjects, the common experience, i.e. treatment, is the most plausible reason for

change. Moreover if the change is noted in a variety of subjects, a more convincing case is made for the treatment. The possibility of history and maturation are unlikely explanations for the change seen in a variety of subjects from diverse backgrounds and settings.

i) Triangulation: The nature of the research topic requires multi-dimensional, multi-target, longitudinal data. Triangulation provides a guard against the accusation that the findings are simply an artifact of a single method, a single data source or simply experimenter's bias. Triangulation attempts to balance the strengths and weaknesses of the quantitative and qualitative approaches. The goal is to capture a more complete , holistic and contextual portrayal of the process, multiple measures may therefore uncover some unique variance which could have been neglected by a reliance on one approach.

a) Data triangulation: In the study a variety of data sources are used, thereby facilitating the cross-checking of information and the consistency of findings. Information derived at different times and by different means can be cross-checked. How far can the data be generalised to other situations, times and subjects? It is hoped that in working with over 50 children from very different backgrounds this problem can be overcome. The consistency of findings generated by different data collection measures is investigated. Observation data is compared with interview data, public and private statements are contrasted, evidence of consistency is examined. Efforts are made to try and maintain contact with persons with as diverse perspectives as possible to ensure a variety of views are heard. Patterns of consistency in the data derived from different sources, along with reasonable explanations for inconsistencies contribute to the overall credibility of the findings.

b) Investigator triangulation: Throughout the project a number of different observers are used, frequently 2 or 3 persons independently analyse the same data thereby reducing the threat of systematic bias in the researcher. Attempts were made to include respondent validation by having the LS and families read and comment on the case studies prepared by the researcher. Moreover, it is hoped that enough information regarding the programme is presented to allow the reader to formulate their own conclusions.

c) Theory triangulation: Multiple perspectives and methods are used to analyse the data thereby checking the consistency of findings generated by different methods. The research draws on both the quantitative and qualitative traditions, the findings from one complementing the other. It is however assumed that the weaknesses in each method will be compensated by the strengths of the other and that the two approaches do not share the same weaknesses or potential for bias.

ii) Evaluator effects: Behaviour is changed by the intrusion of a field worker, according to Patton (1980), the issue is not whether such effects occur, rather the issue is how to monitor those effects and consider them when interpreting the data. One attempt to overcome the problem is for researchers to become 'part of the landscape', however researchers may then become so familiar with the setting that they are unable to objectively analyse what they experience. The problem could be overcome by a series of independent collaborations by various informants. Researchers need to analyse their own involvement and seek various reactions to their analysis. As far as possible researchers should use unobtrusive measures and be explicit concerning why they are present, what they are studying and what they hope to do with the information. A variety of informants should be used including potential critics of the programme. The knowledge gathered is, in part, a function of

who gives it. A careful description of the sources of data is therefore necessary. The social context in which the information was gathered also needs to be recorded. What persons say and do vary according to others present at the time. Explanations of the physical, social and interpersonal context within which data was gathered enhances the replicability of qualitative studies.

The most dependable way of ensuring a positive evaluation is to use voluntary testimonials from those who experienced the treatment. It is dissonance reducing for the client as well as common courtesy to the LS to report improvement (Campbell,1969). One attempt at controlling this problem will be to use independent evaluators, unfamiliar to the families, rather than the LS to elicit an assessment of the value of the programme.

Throughout the study independent reliability checks will be made by persons not involved in the training programme. However agreements between assessors characteristically decrease by about 25% when the raters are monitored without their knowledge compared to when they know their assessments are being checked (Reid,1970). Reliability may therefore decrease quite dramatically once the assessors believe the researcher is not directly monitoring their assessments.

The reactivity in this study is overcome by making it a constant factor. The LSs were informed that 10% of their assessments would be checked by an independent evaluator (IE). The checks would be made a day or two after the LS's evaluations, the LS would therefore be unaware of which of their assessments would be examined. The approach would act as a check on 'instrument decay' due to the passage of time as independent evaluations occurred throughout the period of data collection.

Romanczyk et al (1973) have shown that observers change their style of assessments to match their perception of the unique ways that different assessors apply the behavioural code. The researchers showed that when differences existed among IEs in the application of the code, the observers were able to match these differences. In this study the LSs and IEs did not meet and the LSs were not informed regarding the assessments by the IEs. There was therefore no opportunity to learn the idiosyncrasies of each other's assessments.

The manner in which Ss respond in accordance with the experimenter's hypothesis has been clearly demonstrated (Rosenthal,1966; Rosenthal and Jacobsen,1968). Kent and Foster(1977) observed that when the researcher reacted positively or negatively towards the observer according to the degree of progress of the children, the observers unintentionally exaggerated treatment effects to satisfy the researchers.

In the present study it was obviously impractical to keep the LSs and IEs unaware of the experimental hypothesis. However the IEs were unaware of how the MBD was being applied across subjects and behaviours in relation to the child they were assessing. If the inter-observer reliability remains high throughout the study, when the IE is unaware of the phases of the MBD, the demand characteristics of the study would not appear to be a major threat to the reliability of the result. Feedback to the LS concerning assessment focussed on accuracy rather than any indication of 'desirable' results. Knowing that their data was open to scrutiny by IEs acted as an incentive to maintain standards of accuracy and objectivity.

Design features which may help to overcome the threats of either internal or external validity could jeopardise the other. A balance between the two, trading off strength of

design for relevance is therefore necessary (Cronbach, 1982:115).

The research topic demands a balance between the merits of a quantitative approach, offering an analysis of the reactions of many persons to a limited number of questions, presented in an objectivé, reproducible and concentrated manner; and the claims of a qualitative method which offers depth and detail on a smaller number of persons presented in the form of a holistic, natural enquiry. A trade-off is necessary between bandwidth, the number of questions for which an answer is offered, whether dependable or not, and fidelity, the dependability of an answer to a particular question. This reflects a trade-off between strength of design and relevance, as bandwidth increases, fidelity drops. A researcher who has travelled the path between the quantitative and qualitative traditions concludes:

> the evaluator should almost never sacrifice breadth of information for the sake of giving a definite answer to one narrow question. The cost of answering one question well must be weighed against the cost of leaving other questions unanswered (Cronbach, 1982:xii).

CHAPTER 4: PROJECT IMPLEMENTATION

A : BACKGROUND INFORMATION

4.1 Rationale for the project

CBR has been presented as a panacea, one approach equally relevant for societies as different as St. Lucia and Pakistan. A number of the problems with the WHO evaluation have been discussed in Chapter 2. The practical limitations of relying on traditional services has also been discussed. This research project attempts to examine the relevance and effectiveness of a CBR programme implemented in two rural areas of Guyana over a two year period. The project evaluates how well the basic principles of CBR have been presented and assesses how effectively each of the components is working.

4.2 Guyana

Guyana is located on the Atlantic shoulder of the South American sub-continent. It is bordered by Suriname on the West, Venezuela to the East and Brazil to the South. Guyana is a land of 83,000 sq. miles with an estimated population of .9 million (UNICEF,1987). 90% of the population live on the narrow coastal region where the population density is 25 persons per sq. mile, by contrast, in the vast interior areas the population density is less than one person per sq. mile.

Guyana achieved its political independence from Britain in 1966, and declared itself a Co-operative Republic along Socialist lines in 1970. The economy is based primarily on the production of sugar, rice and bauxite. In 1976 these three commodities accounted for 86.7% of Guyana's total export

earnings (Standing and Szal,1979). Guyana's economy is therefore very vulnerable to fluctuations in world trade.

An examination of the social and economic statistics on the country, prepared by UNICEF(1987) [1] reveal both positive andnegative trends. Infant mortality is declining (from 69 per 1000 in 1960 to 33 per 1000 in 1985), as is the crude death rate (from 10 per 1000 in 1960 to 6 per 1000 in 1985). Life expectancy has risen from 60 years in 1960 to 69 in 1985 and is now 12½ years longer than the world average. Adult literacy has also risen in this period from the 91% in 1970 to 96% in 1985.

The picture is however balanced by other indicators. The GNP per capita is falling from the 1982 figure of US$670 to a figure of $590 in 1984. The percentage of infants with low birth weight (i e less than 2,500 gms) is 18% Standing and Szal(1979:41) claim that for much of the population income levels are not sufficient to meet subsistence needs. They quote a 1971 nutrition study which identifies a high percentage of the population as anaemic. and 1970 unemployment figures of greater than 50% for the 14-19 years age group The percentage of the health budget allocated to health is one of the lowest in the Caribbean (Moody,1981; Hannay,1978).

According to figures for 1985 , quoted in an article in one of the national newspapers (Stabroek News, April 3rd, 1987), Guyana, with a per capita income (Gross Domestic Product) of US$720 is one of the poorest countries in the Americas. Only two countries, Haiti and Honduras, were considered worse off. It should also be noted that the article was written before a devaluation effectively decreased the value of the currency by at least 150%.

1 See Appendix XXV

4.3 Provision for children with special needs in Guyana

Guyana has only one special school which is based in the capital and serves hearing-impaired and intellectually-impaired children. There is a long waiting list for entry to the school. There is also a centre for physically-handicapped children in the capital. A unit for visually-impaired children is attached to a regular school in the capital. There are two small units, catering for disabled children in two of the towns in the rural areas. The capital, which has approximately 23% of the population, has 90% of the provision in the area of special education. The disabled children once admitted to these facilities remain for many years and with the increase in the population few new places are being made available. The degree of population coverage and the annual admission rate are therefore very limited. The ratio of staff to children is very high. A significant gap therefore exists between needs and available services.

B: IMPLEMENTATION OF PROJECT

4.4 Preliminary planning

Before the programme began a series of meetings was held with the following agencies; Ministry of Education, Institute of Adult and Continuing Education, Georgetown Association for Parents of Mentally Handicapped Children. Consultations were also held with a number of professionals in the field of rehabilitation. The project was given good media coverage with two radio interviews and two newspaper articles. [1]

1 See Appendix XXI and XXII for copies of these articles

The project was financially supported with grants from the Canadian International Development Agency (CIDA), the University of Guyana and the University of London. Table 4.1 gives details of the financial support:

Table 4.1 Financial support for CBR project

Local funding (G$)	
University of Guyana	8650
CIDA	5000
	G$13650
Overseas funding (£)	
CIDA	2608
University of London	100
	£2708

4.5 Local Supervisors (LS)

Two groups of LS were recruited, one comprising volunteers and the other nursery school teachers.

i) Volunteers: The programme was offered as a course by the Institute of Adult and Continuing Education (IACE). No academic qualifications were required for the programme. The course was advertised in the mass media and by posters displayed in schools, shops, clinics and places of worship. The programme was organised for a rural area of Guyana, the East Bank of Demerara, to service a number of villages in an eight mile radius of the outskirts of the capital. 200 people were attracted to an introductory meeting to explain the goals of the project. The meeting was organised in conjunction with the Parent- Teachers' Association of the village school. The planned intake was 20 participants, however 60 persons applied and eventually 30 were accepted. Four of these persons never

appeared for any of the sessions. The volunteer programme therefore began with 26 persons. The selection was based on place of residence as the hope was to attract persons from the various villages rather than any special qualifications or aptitude applicants appeared to have. The background information on the volunteers is presented in Table 4.2:

Table 4.2 Background information on volunteers

Sex:	male:2 female:24
Age:	20-29:13 30-39:8 40-49:4 50ys+:1
Race:	African:22 Indian:2 Mixed:2
Religion:	Christian:25 Hindu:1
Background:	urban:3 rural:23
Marital Status:	married:12 single:12 divorced:2
No. of children:	0:7 1-2:6 3-4:7 5+:6
Education:	primary:5 secondary:13 tertiary:8
Occupation:	teacher:9 nurse:5 housewive:6
	clerk:2 technician:2 student:2
Total Income:	G$ 400:9 400-700:2 700-1000:8
	1000-1500:4 1500+:3
Living arrangements:	rent:11 own home:5 live with family:7 other:3

The group composed predominantly females from a Christian, African background and therefore was not fully representative of the multi-ethnic Guyanese population. The average earnings of the group, following the 1987 devaluation, was £47 per month before tax at the official rate, but at the more realistic , officialy -sanctioned parallel rate was only £25 per month. The average age of the group was 32 years and the average number of children per family was 2.7. Six of the group had five or more children of their own.

ii)Nursery school teachers: This programme was organised in co-operation with the Ministry of Education. A high percentage of the population take advantage of the free nursery education which is offered. Children between the ages 3.9 and 5.9 years attend daily from 9-12 am leaving the teachers 'free' in the afternoons for workshops and preparation.

A formal research proposal was submitted to the Chief Education Officer, there followed meetings with the Nursery Co-ordinator, the Research and Planning Officer and the Regional Education Officer of the Ministry of Education.

The Chief Education officer gave permission for the project, allowing the teachers to participate'if they chose to do so' [1]. The Ministry selected 5 schools in a rural area of the country, West Coast Demerara, approximately 12 miles from the capital. The researcher met with the Heads of the schools and subsequently discussed the programme at two meetings for all the teachers. Meetings were then held with the staff at each of the schools separately. Throughout these discussions it was emphasised that the teachers were free to decide whether or not they wished to participate. However all 25 teachers chose to join the programme. The proposal was accepted that the CBR programme could constitute the workshop sessions. The training and practical work were therefore planned for the normal working hours.

1 See Appendix XIX

Table 4.3 outlines background information on the teachers.

Table 4.3 Background information on nursery school teachers

Sex:	male:0 female:25 [1]
Age:	20-29:8 30-39:12 40-49:4 50ys+:1
Race:	African:13 Indian:11 Mixed:1
Religion:	Christian:14 Hindu:6 Muslim:5
Background:	urban:5 rural:20
Marital Status:	married:10 single:11 divorced:2 widowed:2
No of children:	0:10 1-2:8 3-4:4 5+:3
Education:	primary:3 secondary:17 tertiary:5
Qualification:	trained teachers:5 untrained teachers:20
Total Income:	G$ 400-700:18 700-1000:5 1000-1500:2
Living arrangements:	rent:7 own house:8 live with parents:8 other:2

As a group the teachers were more representative of the ethnic and religious composition of Guyana with 11/25 coming from Hindu or Muslim backgrounds. The average age was 34 years and the average size of the family was 1.7 children. 20/25 of the teachers were untrained (ie had no formal qualification for working in the nursery) and consequently earned the equivalent of £25 per month at the 'parallel rate'.

There were therefore no significant differences between the groups in terms of age, sex, marital status and rural background. However the volunteers tended to be slightly better educated and better paid, they also had larger families to look after.

1 This data does not include the 4 teachers who either transfered, resigned or were on maternity leave.

4.6 Intermediate Level Supervisors (ILS)

The programme was co-ordinated by the researcher, an Educational Psychologist, and by a Senior Physiotherapist. The Physiotherapist has worked for WHO as a consultant in the area of CBR and was involved in the initial evaluation of the WHO field projects in Sri Lanka. The role of the ILS was to co-ordinate the training programme and monitor and support the work of the LSs.

4.7 Training of LSs

The training programme followed the detailed outline prepared by WHO (Mendis and Nelson,1983) [1]. The training programme began in September 1986 and continued until December 1987. Table 4.4 outlines the structure of the training sessions.

Table 4.4 Structure of the training programme for LSs

	Term one	Term two	Term three	Term four	Total
Volunteers	17x2hrs	13x2	8x2	6x2	88 hrs
Nursery teachers	10x2hrs	6x2	5x2	4x2	50 hrs

In addition to the training inputs provided by the 2 ILSs the programme drew heavily on the services of a number of resource persons. Tables 4.5 and 4.6 illustrate the help that was given.

1 See Appendix VI

Table 4.5 Resource persons on training programme for volunteers

Resource person	No of sessions (Total=44)	% of sessions
Researcher	16	36%
Physiotherapist	9	20%
Researcher and Physiotherapist together	8	18%
Teacher of the deaf	4	9%
Parents of disabled children	2	5%
Medical doctors	2	5%
Teacher of the blind	1	2.3%
Teacher of the mentally retarded	1	2.3%
Lecturer in Adult Education	1	2.3%

Table 4.6 Resource persons on training programme for nursery teachers

Resource person	No of sessions (Total=25)	% of sessions
Researcher	21	84%
Teacher of the blind	1	4%
Teacher of the deaf	1	4%
Paediatrician	1	4%
Parents of disabled children	1	4%

The training sessions in the first term focused on; survey methods, approaches to identifying children with disabilities, use of the Portage Checklist, introduction to the WHO Manual, examination of the concept of CBR and an introduction to various categories of special needs. Once the LSs had identified children to work with the training sessions drew on the experience of various professionals to outline ways of

helping children with special needs in the areas of movement, hearing, seeing and learning. Role play sessions were organised to examine ways of communicating with other adults. The Parents' Association of Mentally Retarded children shared their experiences of what it meant to have a handicapped child in the family.

The second term focused on specific ways of helping children with disabilities, again drawing on the expertise of the professionals in the various areas. A series of practical sessions were held focussing on the preparation of teaching and mobility aids. Methods for stimulating play in the handicapped child were examined.

The final two terms focused on the presentation of a series of case-studies with the participants and parents discussing possible teaching approaches. A problem-solving approach was nurtured. Sessions were presented on counselling to try and develop the sensitivity of the LSs to the needs of the child and the family. Lectures were also given on services available within the community, methods of prevention and record-keeping. Time was allocated for the planning of public meetings and radio programmes to increase community awareness regarding disability. The professionals maintained their contact throughout the year presenting lectures on specific topics as requested. Appendix VI compares the inputs made on the 'Volunteer' and 'Nursery Teacher' programmes. As can be seen from Tables 4.4 to 4.6 the inputs were more varied and comprehensive for the 'Volunteer' than the 'Nursery' sample.

4.8 Identification of children

Each LS was asked to work with two disabled children between the ages of 3 and 8 years. 53 children were identified to work with. Table 4.7 gives a breakdown of how the children were

identified, and Table 4.8 notes the aetiologies of the disabled children involved in the programme.

Table 4.7 Method of identification of disabled children

	Volunteers		Nursery teachers	
	N	%	N	%
House-to-house visits	23	79%	2	8%
Referral by professionals	4	14%		
Referral by parents	2	7%	2	8%
Identified within nursery			20	84%

Once it appeared that the child was eligible for the programme the researcher contacted the family to explain the project and to see if they wished to be part of the service. In each case the child was assessed on the Griffiths, any child scoring less than 78 on two or more subtests was considered eligible for the programme [1]. All children that met this criteria were accepted for the programme regardless of the nature or severity of the disability.

Table 4.8 Aetiology of clients, overall and within each area

	Overall		Volunteers		Nursery	
	N	%	N	%	N	%
Undiagnosed	3	6%			3	13%
Cerebral Palsy	3	6%	3	10%		
Epilepsy and MR	22	42%	13	45%	9	38%
Downs Syndrome	5	9%	3	10%	2	8%
Deaf	7	13%	4	14%	3	12%
Speech problems	7	13%			7	29%
Physical handicap	6	11%	6	21%		

1 See Revill & Blunden,1977 ; Bidder, Hewitt & Gray,1983.

4.9 Home training

The LSs were directed to identify someone in the child's home through whom the training programme could be introduced. The 'trainer', as they are called in WHO terminology, could be a relative, neighbour or teacher, however in the great majority of cases it was the child's mother. Each time the LS visited the home they assessed the child using the Portage Checklist. The LS and trainer then decided on a teaching objective for the next week. The LS would then try to teach the child the skill by breaking it down into constituent parts. The trainer would observe the interaction with the child and would then carry out the task themselves. The LS and trainer would then discuss the exercise. In these practical sessions the LS was encouraged to explain both the general principles of the home teaching model and outline how the skill could be task-analysed in a simple manner. The Portage Checklist was used to help in discussing appropriate objectives for the child. The Checklist was intended to help parents formulate realistic expectations of the child's ability.

Much of the training of the LSs focused on ways of presenting the teaching ideas in a way to fit into the routine of the family and so that it could be perceived as a form of play rather than a formal act of teaching. The LSs were not attempting to impose a rigid training schedule of X minutes per day. The LSs were encouraged to appreciate the many competing demands made on the mother's time in the home.

As the programme continued it became clear that the families had wider needs than those of the handicapped child alone. A number of the mothers drew on the LSs for emotional and psychological support.

4.10 Teaching materials

A request was made to WHO to provide copies of their training Manual (Helander, Mendis and Nelson.1980) for each of the participants. The request provedunsuccessful. Summaries were therefore made of the training packages for children who have difficulty with; hearing and speech, learning, moving, seeing and children who have fits. Each of these packages was reproduced as a separate handout and sufficient copies made so that relevant sections could be left with the families. Handouts were also produced from the WHO Manual on the development of play, the promotion of independence in mobility and self-care .

Each LS had a copy of the Portage Checklist. In addition the LSs were given booklets of teaching ideas on the following areas; motor, self-help, language, socialisation and cognitive development. These ideas were taken from the Portage materials. Teaching suggestions were also incorporated from Zimcare Trust in Zimbabwe (Mariga and McConkey,1986). A video-course on nurturing the play of handicapped children by McConkey and Gallagher, called 'Let's Play', was also used.

The training of the LSs focused on how to use these materials in a creative, problem-solving manner rather than adopting a cookbook approach. Practical exercises were conducted in the classroom sessions with parents along with their disabled children. Workshop sessions would then follow focussing on the selection of appropriate materials for the child.

In a follow-up programme it is hoped to produce a coherent and structured set of materials directly relevant to a Guyanese context rather than supplying the LSs with a series of handouts and booklets from a variety of sources.

C : **ASSESSMENT OF PROJECT**

4.11 Multiple Baseline Design (MBD) assessment

i) Introduction: Where possible the LS worked with more than one child. Treatment was introduced at different times for each of the children. The MBD was also applied across behaviours in each child. The LS selected one of the Portage areas (eg self-help, language etc.) and focused on this area while using the other areas as extended baselines. Once behaviour reached an appropriate criterion in this area, treatment was introduced for one of the other areas while continuing to take measures on the former area. The design therefore attempted to introduce the MBD across both subjects and behaviours. A minimum of 3 data points were taken over a 2 month period in the baseline. Where any fluctuations were observed in performance the baseline was extended until an acceptable level of stability was established.

MBD relies on frequent assessments of the subjects over time, 'the quality of measurement (therefore becomes) the cornerstone of all applied work' (Barlow, Hayes and Nelson,1984:159). Measurement is on-going, it therefore needs to be rapid, easy to score and cheap. The measurement should be clearly specified, public and replicable in all respects. McConkey(1986) cautions that meeting these criteria in the West is difficult enough and is obviously far more demanding in a LDC context.

ii) Portage assessment: A frequent criticism of assessment is that 'test behaviour' is often unrepresentative of 'real behaviour'. The Portage Checklist was adopted because of its attempt to assess what the child does in daily life by providing a detailed list of everyday behaviours many of which

can be observed in the natural environment. The child was assessed by the LS on each visit to the home with the Portage Checklist. All the assessments were done in the child's home, using the same assessor on each occasion. Efforts were made to rely as little as possible on parental reports and to have the child actually perform the activity.

The Jamaican adaptation of the Portage Checklist (Caribbean Institute of Mental Retardation,1981) was used. This was further adapted by a group of 10 Guyanese educators and health workers who analysed each of the items. The group did not feel that any major areas of development were missing from the checklist, they however deleted 5 of the items as being irrelevant to a Guyanese context [1].

iii) Reliability of assessments: Independent reliability checks were made by persons not involved in the training programme. The problems of the reliability of human assessment have been examined earlier. Assessors could become bored with the task of measurement over an extended period or could in fact become more skilled at the task as the experiment continues. The assessors may simply conform to what they feel is the experimental hypothesis.

A number of safeguards were introduced in an attempt to make the assessments as reliable as possible. The more ambiguous the dependent measures the greater the possibility of inaccuracy. The Portage items were therefore reviewed with a variety of educators, health personnel and parents to see which were problematic.

1 See Appendix 1

The ambiguous items were re-written as behavioural objectives. An example of the way in which the items were changed is:

a) original item: child can identify, by pointing, pictures of everyday objects presented in an array when asked 'show me'.

b) re-written item: child can identify, by pointing, the following pictures; cup, ball, plate, doll, spoon, knife, shoe, shirt, presented in any order in an array of 5. The criteria of success is to be correct on 3 successive occasions for each picture. (The full list of behavioural objectives is presented in Appendix IV).

In a further bid to standardise the presentations as far as possible the pictures needed for checklist items were prepared for the assessors [1].

Before the experiment began a series of training sessions on the Portage Checklist were conducted separately for the IEs and LSs. Each of them also assessed children in the field along with the researcher, immediately following the assessments any disagreements were discussed.

The assessment code needs to be used in a consistent manner throughout the study. On two occasions the assessments of the LSs and IEs were re-calibrated by on-going training sessions. This was done to help meet the threat of 'observer drift'. Moreover mid-way through the study a new IE was introduced, as the person was newly trained it could be presumed they would be following the training principles more closely. The LSs and IEs did not meet until the end of the project thereby overcoming the problem of consensual drift.

The LSs were told that 10% of their assessments would be checked by an IE, however they did not know which of the

1 See Appendix V

assessments would be checked. The checks were done by the IE one or two days after the LS's evaluation. It was hoped that reactivity might be controlled by making it a constant feature of the experiment. The presence of the IE was explained in terms of the reliability of the results rather than checking on the honesty of the LS, as such it presented no problems to the LSs

It was impractical to keep the experimental hypothesis secret from the IE, however in the sense that the IE was unaware of which behaviour in the MBD was under treatment, the assessments were blind. The researcher was careful to stress the need for accuracy in the results rather than desirability.

iv) Calculations of inter-observer reliability:The correlation between the internal and external assessor provides a practical check on the consistency with which response definitions are applied over time. A distinction however needs to be made between 'agreement' and 'accuracy'. As there is no accepted criteria of the 'actual' performance one needs to settle for investigating agreement rather than accuracy. The assumption is that if two observers independently record the same behaviour their data probably reflects what the person is doing.

The estimate of agreement between the two observers, over and above chance, is calculated using Kappa. Kappa is an improvement over the Pearson Product Moment Correlation in that agreement is calculated separately for occurrence and non-occurrence of behaviour thereby providing additional data which conveys how observers actually concur in their observations. Eight trained teachers were employed as IEs. The results of the assessments are presented in Table 4.9.

Table 4.9 Inter-observer reliability checks on Portage assessments using Kappa

Area	No.of checks	Range of Kappa	Average Kappa
Volunteers	44	.75 to .95	.86
Nursery Teachers	17	.85 to .91	.88

Out of the 61 reliability checks, 13 (21%) are in the range of .75 to .85 and 14 of the assessments (23%) are above .90 (O'Toole,1989b)

v) Analysis of results: The problem of analysing the data in N=1 studies has been termed the 'punishment factor' (Stanley,1985). Few of the available procedures of statistical analysis are straightforward enough for the clinical setting as is suggested by their infrequent use by practioners (Kratochwill,1978). Repeated measurements om the same individual, a key feature of N=1 studies, results in the scores for each assessment being related to the subsequemt assessment, thereby producing correlated errors. Serial dependency is therefore basic to N=1 research and this limits the use of applied parametric statistics as the assumption of independence of scores is violated (Halil,1985:84).

Time Series Analysis (TSA) is one proposed solution. TSA extracts serial dependency from the data and transforms raw scores to uncorrelated or serially independent scores, however the price that has to be paid for this statistical sophistication is considerable; a minimum of 10 data points in baseline (Herzen and Barlow, 1976:288) and up to 100 assessments over the course of the experiment (Stanley,1985).

Tryon(1982) has suggested a simplified form of TSA which requires only 8 data points, however the status of various statistical tests for N=1 data is unclear. TSA is not widely used in applied clinical research (Stanley,1985). The effects of failing to meet various conditions (eg high number of data points) on the validity of TSA is not yet determined.

In view of the problems with statistical treatment of N=1 designs it is not surprising that a number of researchers advocate visual rather than statistical analysis of the data.

Visual analysis allows others to judge for themselves whether an intervention has merit and whether the fimdings are reliable. Once graphed, the effectiveness of the intervention could be judged by change being of sufficient magnitude to be apparent to the eye. It is argued that the insensitivity of the approach is a strength in that only powerful effects would be judged as being significant (Kratochwill,1978:111)

A major problem with visual analysis is the lack of a clear criteria for determining whether a particular treatment shows a reliable effect which permits, if not encourages, subjectivity and inconsistency in the evaluation of intervention effects (Jones, Weinrott and Vaught,1978). The decision rules for judging the significance of an effect therefore need to be made explicit. In this study for a treatment to be judged significant, at least 4 out of the following conditions need to be satisfied [1]:

a) Trend direction: There should be a change in trend direction towards improvement over phase changes.

1 The method used is that advocated by Tawney,J.W. and Gast,D.I. in 'Single Subject Research in Special Education'. Columbus, Ohio, Charles Merrill (1984).

This is done by calculating the celeration lines [1] in each phase.The null-hypothesis would suggest no change in performance across phases, if so, the celeration line of A should be a valid estimate of the celeration line of B. The celeration line for condition A (baseline) and condition B (treatment) will be calculated. The criterion is that improvement should be seen over the AB period.

b) Trend stability: The change in trend direction should conform to a 15% stability criterion to see if the data is sufficiently stable to provide a convincing demonstration of experimental control when experimental conditions are changed. 15% of the highest data point values of condition A will be calculated, an envelope is then drawn around the condition A trend line which represents the acceptable stability criterion. The same is done for condition B. The percentage of data points which fall within the trend stability range is then calculated.

c) Change in level: Observations will be made to see if there is a change in level at the point of introducing a treatment.

1 Summary of Split-Middle Method steps: the data in condition A is divided in half. Each half is then divided in half again. The median value for each half of the data is then found and a line drawn parallel to the abscissa that intersects the mid-date line. A line is drawn which passes through the points of intersection found in the previous step. To find the split middle line, the line , found in the previous step, is adjusted so that there are an equal number of data points above and below the line. The above steps are then repeated with condition B.

d) Absolute level change: An absolute change in level over A and B should be noted to see if there is improvement, deterioration or no change.

e) Percentage of overlap: The range of values in A will be observed and the number of data points which fall within the range of A noted. The lower the percentage of overlap, the greater the impact of the treatment if the change is in a positive direction. The percentage of overlap between A and B should be less than 5%. Moreover the more closely in time that change occurs after the experimental conditions have been altered, the clearer the intervention effects.

4.12 Griffiths assessment

Tests of early childhood development are plagued with problems of reliability and validity even when given to able-bodied children (Sandow,1979). These problems become more accute when applied to handicapped children (Schindele,1985; Goodstein,1982).

The Griffiths scales (Griffiths,1970) were initially designed to enable a detailed differential diagnosis of mental status in handicapped children in addition to measuring general ability in able-bodied infants. The test provides a detailed profile of six skill areas and offers a sensitive evaluation of the developmental progress of the child.

The test was standardised on a sample of 2,260 children,(Griffiths,1970:17), constituting a representative cross-section of the British population (op cit:20). The manual reports consistently high correlations between Griffiths and Terman-Merill I.Q. scores (op cit:70) suggesting a substantial common factor between the two tests in spite of the

considerable difference in subject matter of the actual tests. Test-retest data based on 250 persons is reported yielding a correlation of .77 (op cit:74). Attempts have therefore been made to validate the test and ensure its reliability.

The contents of the test was discussed with the Parents' Association of Mentally Retarded Persons. The members of the Association felt that the structure and contents of the test were appropriate to a Guyanese context. Some minor changes were made to the Reasoning Scale to reflect a Guyanese experience.

The cultural bias in formal testing is well-recognised; children in LDCs do not engage in prolonged, dyadic interaction with an adult and are not encouraged to display their intellectual competence to strangers (Serpell,1984). With this in mind the assessment sessions were presented as a form of play rather than a formal testing situation. The Griffiths test was therefore used because of the depth and thoroughness offered and because of the relatively culture-free aspect of the test.

At the beginning of the project all the children were assessed on the Griffiths test by the researcher. The children were retested at the end of the programme and at a 6 months follow-up. As little reliance as possible was put on accepting parental reports, the emphasis was placed on getting the child to perform the behaviour. The Griffiths test was used to asses whether the child's score on a standardised development test increases faster following treatment than before.

Independent reliability checks of the researcher's assessment of the Griffiths was done by a Clinical Psychologist. The IE independently scored the child's performance with the researcher on 9 occasions. For each set of scores the difference between the scores was calculated and expressed as a percentage of the researcher's score. The mean percentage

agreement was then calculated over all reliability checks. The mean percentage agreement for the Griffiths was 94% [1]. The range of agreement was 88% to 97%. These results compare favourably with other studies reported in the literature (cf Revill and Blunden,1979).

4.13 Need for appreciating different perspectives

The project's effectiveness cannot be evaluated solely in terms of the child's progress on a standardised test or developmental checklist. Limiting the analysis to the child's 'progress' yields only a partial reflection of the value of the programme. Quantitative gains need to be balanced with a qualitative analysis of the process involved. A range of questions need to be examined and a number of different perspectives presented in an attempt at responding to the questions.

4.14 LS perspective

i) Diary observations: Each LS was asked to keep a detailed diary concerning their involvement with the child and the family [2]. The aim of the diary was to obtain an insider's view of what was happening on the programme. The LSs were asked to reflect on their own involvement and to examine their own influence on the course of events. This was regarded as a useful method for analysing topics which are not easily quantifiable.

1 See Appendix XXXXII
2 See Appendix VII

ii) Evaluation of programme: Each of the LSs were interviewed by an IE at the end of the training programme in the hope of gaining an insight into what it meant to be a part of the project [1].

4.15 Parents' perspective

i) Introduction: The literature documenting the parental 'response' to having a handicapped child has already been examined, one aim of the present research is to investigate the relevance of that literature to a Guyanese context. Mittler, Mittler and McConachie (1985:5) suggest the response is a reflection of the lack of any assistance, a further objective of the study therefore is to explore how the attitudes of parents are influenced by the training programme.

Discussions with parents and professionals helped to define the specific emotional and attitudinal goals at which the intervention should be aimed, these included; accepting the disability, increasing self-confidence and appreciating the child's achievements. The assessment measures were therefore constructed around the specific objectives of the programme. A battery of questionnaires and interview schedules was therefore developed to provide qualitative and quantitative measures of the parents' perspective. The questionnaires were administered by the LSs at the beginning of the programme and by an IE at the end of the project and again at a 6 month follow-up. Few studies appear to relate the effectiveness of early intervention programmes in meeting the emotional needs of the parents. It is apparently taken for granted that any form of help would automatically be accepted as a good thing.

1 See Appendix VIII

The validity of the instruments is approached by asking the same questions in different ways and by comparing the responses with the observations of outside observers. The nature of the instruments varies from highly to loosely structured and presents the questions in different forms to the mother. The measures were pilot-tested with a group of 16 parents, members of a parents' association of disabled children. The results of the pilot-testing are presented in relation to each particular method.

ii) Interviews: A standardised open-ended interview schedule was used with the exact wording and sequence of questions pre-determined. The initial schedule was modified and simplified following the pilot-testing with the parents' group. The interviews were administered by the LS at the beginning of the programme [1], and again by the IE at the end of the programme [2], and 6 months after the programme had finished [3].

The two follow-up interviews were tape-recorded (the first was not as the tape-recorders were not available at that time). Tape-recording was presented as a convenient, labour-saving device, ensured comprehensive answers, guarded against faulty recollection by the interviewer and allowed the interviewer to concentrate on the discussion with the parent. In each case the parents' permission was sought for using the recorder.

An attempt at meeting the problem of 'grateful testimonials' was made by using IEs for the follow-up interviews in the hope that parents would be more candid regarding the programme to an outsider than to the person who was responsible for the training.It was not felt that this affected the first interview

1 See Appendix IX for Pre-Training Interview Schedule
2 See Appendix X for Post-Training Interview Schedule
3 See Appendix XI for Follow-Up Interview Schedule

as this was conducted in the first weeks of contact with the parents.A sample of the parents was also interviewed by the researcher. During these visits the parents were encouraged to discuss the help given by the LS, no notes were taken as the researcher did not wish to give the impression of checking -up on the LS. The LS were not present on these visits . Immediately after these visits the researcher noted the main comments made.

The problems of distortion are well recognised, however there appears to be no other practical method of collecting much of the data. It was however emphasised that the material was confidential, that there were no right answers, and that the questions posed were important and of potential value to others.

By asking the same questions of all persons the comparability of responses was ensured. The data was complete for each person on the topics addressed in the interview and the actual questionnaire used is available for examination. Interviewer effects are reduced by asking the same question of each respondent. The interview is highly focused thereby ensuring the time of the interviewer and the family was well utilised.

However these advantages are won at the possible expense of constraining the naturalness of the interaction. The method has been criticised for the lack of flexibility in relating the interview to the particular family and their circumstances and for not allowing the interviewer to pursue issues which were not anticipated when the schedule was written. One attempt at overcoming this final criticism was made by leaving the end of the interview open thereby allowing the interviewer or parent to pursue any subject of interest.

The mothers' responses were transcribed on a series of forms for each question. The responses were sorted into categories by two IEs. Each evaluator made a list of the categories of responses for each question. In cases where there was no initial agreement concerning how a response should be coded the IE discussed the item together to see if an agreement could be reached. In the cases where there was no agreement the response was placed in the 'other' category. The percentage of responses placed into the 'other' category because of lack of agreement between the IEs was 7% for the 'volunteer' sample and 5% for the 'nursery' sample.

iii) Questionnaires

a) Malaise Inventory [1]: The inventory was devised by Rutter, Tizard and Whitmore (1970) to detect emotional disturbance in mothers . Mothers are presented with a series of statements, eg 'do you often have backache?' to which they simply respond 'Yes' or 'No'. The items selected are commonly accepted symptoms of depression. The scoring is a simple summation of 'Yes' and 'No' scores. Any score above 5 positive responses is regarded as, 'above average disturbance'.

The Parents' group pilot-tested the original Inventory and found it to be clear and simple to understand, some minor changes were made in the wording of some questions. A test-retest of the Inventory, with N=13 completing the Inventory two weeks later revealed r=.92.

The Inventory is completed by mothers themselves thereby reducing the possibility of interviewer bias. The test is short, easy to administer and easy to score. There are however

1 See Appendix XII

limitations. Some of the items relate to past events which need not relate to present circumstances. The words 'often' and 'usually' are used repeatedly and lack precise definition. Scoring is done in a simple cumulative manner, however equivalent scores are not , in themselves, indicative of equivalent symptomology. Despite these problems it is 'the most widely used scale of its type and the best available' (Bradshaw and Lawton,1978).

b) Self-Rating Scale [1] : The scale, devised by Judson and Burden(1980), attempts to measure changes in attitude of the mother as a result of receiving treatment for the child. The scale is based on the Semantic Differential with a series of bipolar scales with the mothers placing themselves on a seven-point scale on each pair of the items.

The pilot group of parents suggested some changes to the scale. Five of the bipolar scales were removed because they were regarded as too abstract [2]. Numerals 1 to 5 were substituted for the original 7 blank boxes that were placed between the statements to simplify the task. Some of the language used in the original scale was also simplified [3].

1 See Appendix XIII

2 The scales excluded were: relaxed/anxious, cold/warm, active/passive, indulgent with the child/firm with the child, and comfortable with medical people/ill at ease with medical people

3 The following changes were made : 'don't trust' for 'wary','warmth' for 'affection', and 'not able to share my worries' for 'alone with my worries'

The questionnaire was presented with the following instructions:

> Here is a list of words with their opposites. Between each of the pairs of words are the numbers 1 to 5. Think of yourself in terms of each pair of words in turn and then put a circle around one of the numbers. The more you think one of the scales applies to you, the nearer to that end you circle the number.

The scales which are related were grouped together in four categories: a) mother's own feelings
b) mother's interaction with the child
c) mother's perception of child's progress
and d) mother's relationship with others.
The group means on these four categories, before and after treatment, were compared and assessed. The significance of the changes were assessed using the t test.

The construct validity of the scale could be derived from the fact the scale examines a number of the typical reactions mentioned in the literature concerning having a handicapped child. There should be a significant correlation between high depression scores recorded on the Malaise Inventory and low self-rating scores on this scale. The Spearman correlation between the two was .53, with N=22, which is significant at the .01 level, thereby reinforcing the construct validity of the scale. A test-retest of the scale , with N=13, over a one month period revealed r=.88.

The internal consistency of the scale was assessed by measuring the agreement between related items in the scale. Table 4.10 gives the results of the correlation.

Table 4.10 **Pearson correlation between related items in the Self Rating Scale**

Items	Volunteers N=22	Nursery teachers N=18
2/3	.52 **	.75 **
5/6	.77 **	.79 **
7/8	.76 **	.68 **
14/15	.53 **	.47 *

* sig at .01 level **sig at .05 level

The scale would therefore appear to have high internal consistency. The scale is easy to administer and quick to complete, it allows a fairly wide response choice and the results can be presented in a clear visual manner.

c) Child Rating Scale : Direct measures of attitudes can be distorted by defence-mechanisms, this indirect method is an attempt at overcoming this potential problem. Parents were asked to compare their child with 'most other children' and with the 'ideal child'. The assumption is that the discrepancy between the evaluations would be related to an indirect measure of parental disappointment concerning their disabled child.

The original scale (Worchell and Worchell,1961) was pilot-tested on the Parents' group. The original list was felt to be unnecessarily long and the potentially confusing items were therefore omitted [1].

1 The following items were excluded from the original list: alert, ambitious, busy, competitive, confused, defiant, dependable, docile, dominating, inquisitive, jealous, meddlesome, merry, nagging, negative, possessive, reckless, self-sufficient, spoiled, stable and withdrawn.

The final list of words were arranged alphabetically in a vertical list, followed by 3 columns, labelled:

a) 'my child is',

b) 'I wish my child was',

and c) 'most children are'.

The numbers 1 to 5 were printed in each column next to each trait, indicating how much of the time the trait was applicable. The instructions read:

> We would like to get a better idea of how parents see their children and the children of others. Look at the list of words below. Take each word separately and use it to complete the sentence which says: 'my child is...' The first word in the list is aggressive, so the sentence would read, 'my child is aggressive.'
> Then decide how much of the time this statement is like your child (ie typical of him in general) and rate him on a scale of 1-5 according to the following key:
>
> 1: never 2: sometimes 3: half the time
>
> 4: frequently 5: always

For column two, the mother rated the child in terms of how she would like the child to be and in column three rated the child in comparison with most other children.

Three indirect measures of the child are produced:

i) ratings of own child in column 1

ii) discrepancy between own child and ideal child; columns I and II

iii) discrepancy between own child and most children; columns I and III

As traits are both positive and negative the ratings on the negative traits were reversed. Two judges independently rated the items as positive or negative. Agreement was reached on all items, except 'aggressive' and 'anxious' where this was resolved through discussion and by inspection of the ideal ratings on those traits. Absolute discrepancies between columns

I and II and algebraic discrepancies between I and III were noted, item by item.

The Parents' group rated the test as having high face-validity. A test-retest of the scale, with N=13 over a two week period revealed r=.86.

It would be of interest to investigate the relationship between parental attitudes towards the child, as indicated on this scale and effectiveness on the CBR programme.

d) Sentence Completion Questionnaire [1]

A modified form of the Sentence Completion Questionnaire (Thurston,1959) was used. The mother was presented with a semi-projective device being asked to complete a series of sentence stems (eg 'when I think of my child I feel...'). The original scale was developed specifically to determine the attitudes and emotional reactions of parents to their handicapped children. The scale investigated such areas as; initial reaction, ability to share feelings, understanding of causation, attitude to the future and reactions of the community.

The original scale began with 100 incomplete sentences generated by Thurston from the relevant literature and from practioners. 45 of the items were selected for the final form based on their perceived relevance and their potential for yielding rich responses. The final questionnaire was designed to be long enough to yield reliable information on the areas of interest and yet short enough to encourage responses from as many parents as possible.

In consultation with the pilot-group of parents of disabled children the original Questionnaire was reduced to 16 items for

1 See Appendix XV

ease of presentation. The pilot-group selected those items they felt to be most relevant to this study. The mothers were asked to complete the stems orally. this was done in an interview with an Independent Evaluator which was tape recorded.

The semi-projective technique was selected because of the freedom of response that it allows, encouraging the mothers to express their feelings in whatever way they wish. The questionnaire is also easy to administer, requiring a minimum amount of time and supervision. Moreover the pilot-group of parents found the open nature of the questionnaire attractive.

No simple methods of analysing the data are offered however,Thurston writes:

> it is recommended that there be no fixed, absolute rules for the analysis and interpretation of the questionnaire...a flexible approach is recommended (Thurston,1959:154)

In this study the responses of the mothers were recorded verbatim on a series of forms. The responses to each question were sorted into categories by two evaluators who worked independently. Before the responses were sorted each evaluator made a list of the categories into which the responses for each question could be placed. In the cases where there was no agreement between the evaluators as to how a response should be categorised the response was placed in the 'other' category.

The percentage of responses placed in the 'other' category, because of lack of agreement between the evaluators, was 6% for the volunteers and 5% for the nursery teachers.

4.16 Researcher's perspective

Throughout the project the researcher kept a field-work journal, a running account of the conduct of the programme, recording the significant events and activities of the

innovation and including reflective comments on the process of the intervention. The journal included such issues as; constraints under which the programme was operating, how the programme was perceived by participants, what the LSs did on field visits and the confidence the researcher had in the data being gathered.

4.17 Summary

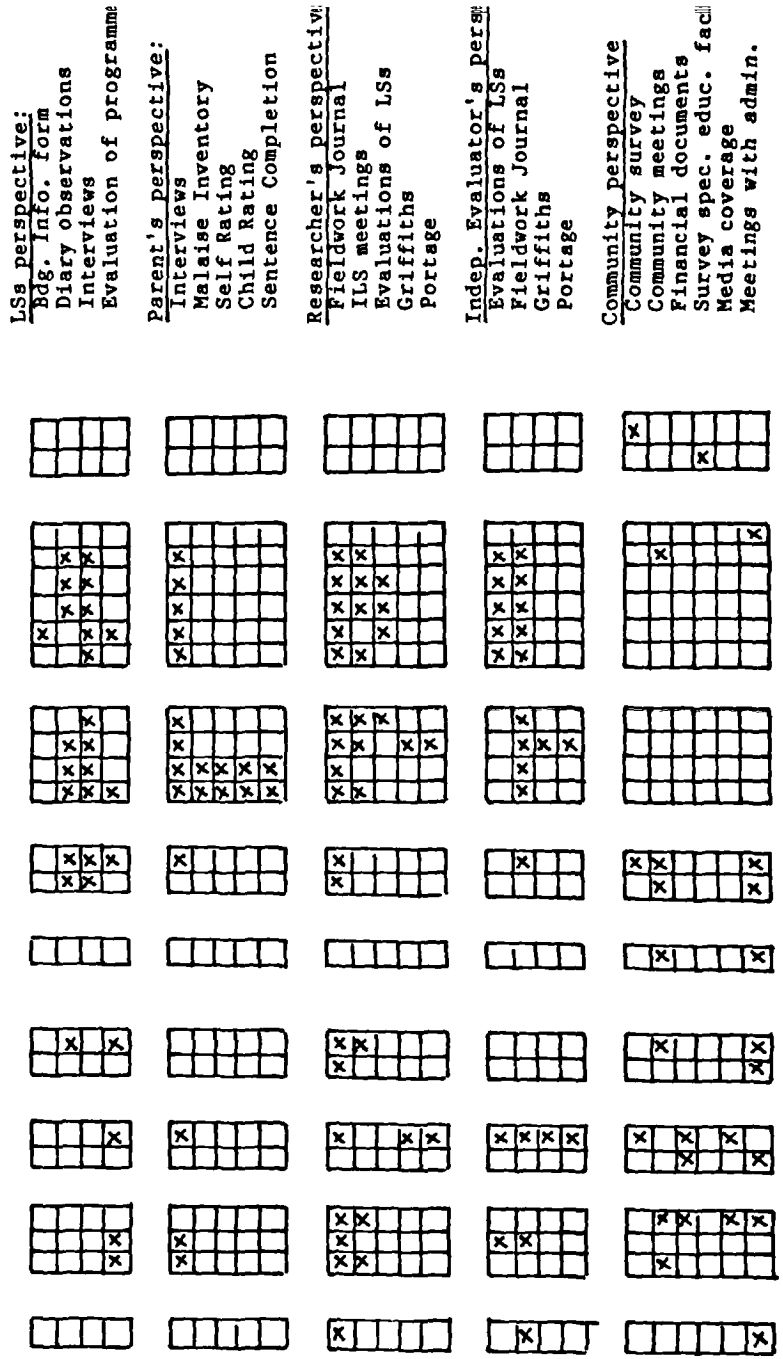
The evaluation attempts to use a multi-dimensional, multi-target, longitudinal approach with a battery of measures thereby counter-balancing the strengths and limitations of individual methods. The goal is to investigate which strategies of the intervention facilitates which areas of competence in the child and their families, to examine how the characteristics of families interact with the programme and how the programme affects the parent-child interaction, and parent and child competences.

Table 4.11 presents an overview of what assessments were carried out in the project and when. Table 4.12 outlines which aspects of the data will be used to respond to which of the research questions posed in Chapter 3. Chapter 5 attempts to evaluate the effectiveness of the innovation.

Table 4.11 Overview of assessments carried out on the project

Date	Parent's perspective	LS's perspective	Researcher's perspective	Independent Evaluator's perspective	Community perspective
Sept 1986	Battery of assessments: i) Malaise Inventory ii) Self-Rating iii) Child Rating Scale iv) Sentence Completion v) Pre-training interview conducted with parents over two-week period Oct/Nov 1986	Background Information Form	Pilot test of all questionnaires with group of parents of disabled children (Sept 1986)		
Oct		Diary: kept by LS, noting involvement throughout the programme	Portage: training of LSs and IEs		
Nov					
Dec					
Jan 1987		Portage: on-going assess. of children throughout project	Griffiths: all children assessed Oct/Nov 1986	Reliability tests: on-going monitoring of children using Portage	
Feb					
Mar			Field Work Journal: kept throughout project	Calculation of Kappa with LSs assessments Jan-Nov 1987	
Apr					
May			On-going meetings between ILSs		
Jun					
July				Fieldwork Journal: kept throughout project	
Aug					
Sept	Post-training interview and questionnaire battery administered in extended 2 hr meeting between parents and IE (Nov 1987)		Observations of LSs with children Oct-Dec 1987	Reliability test: psychologist monitors researcher's assessments on Griffiths Test Oct-Dec 1987	Survey of 4000 persons in one village Oct 1987
Oct		Interview with IE evaluating programme (Nov 1987)	Griffiths: post-test assessment of children		
Nov		Questionn. evaluating prog. (Nov 1987)			
Dec					
Follow-up	Follow-up Interview with IE (June 1988)		Griffiths/Portage: follow-up assessments	Griffiths/Portage follow-up assessments	
			Interviews with LSs & families		

Table 9.14 Application of assessment data in responding to research questions



1) Is the rehabilitation of the disabled a locally perceived need?
- * what is the magnitude of the problem of disability ?
- * how adequate/appropriate is the available provision?

2) Is the concept of simplified rehabilitation a viable response ?
- * work within what infrastructure?
- * training of Aux/Vol realistic model?
- * are Aux/Vol motivated for the task?
- * are Aux/Vol accepted by parents?
- * what makes an effective LS?
- * what training necessary?

3) Is parental involvement culturally appropriate in a LDC context ?
- * do parents accept the role?
- * are parents effective in the role?
- * do attitudes of parents change?
- * any negative effects of programme?

4) Is community involvement a realistic expectation ?
- * how can community become involved?
- * do attitudes in community change?

5) Does CBR establish meaningful links with IBR services ?
- * attitudes of professionals to CBR?

6) Is CBR a realistic way of assisting high numbers in need ?
- * how many could be helped with CBR?
- * close gap between need and provision?

7) Is the programme cost effective ?
- * meaningful gains in view of resources used?
- * programme financed at a level which could be maintained ?

8) What are the essential features of introducing an innovation?
- * what planning is required for an effective innovation ?
- * what method of training/supervision is effective ?
- * how crucial is the role played by the co-ordinator?

9) In what ways does the WHO model need to be supplemented ?
- * adaptations to the model?

CHAPTER 5 : RESULTS

5.1 Introduction

Table 2.1 in chapter 2 outlined the major questions this study hoped to address in evaluating the appropriateness and effectiveness of a CBR approach to disability in the third world context of Guyana. This chapter will present the data from the study which attempts to respond to those questions. Findings will be drawn from both quantitative and qualitative sources.

5.2 Magnitude of the problem

The rationale for CBR has been established on a series of international reports which highlight the magnitude of the problems of persons with disabilities and which stress the inadequacies of IBR facilities in meeting the pressing needs.

One objective of the research was to ascertain the size of the problem in a rural area of Guyana and to examine how the needs of the disabled were viewed by the community.

A systematic survey of one village was therefore carried out. 34 persons took part in carrying out the survey including the participants and members of the community. A series of training sessions were conducted focusing on the use of a modified form of the WHO survey questionnaire [1]. To achieve consistency, interviewers were instructed to ask the questions exactly as presented throughout the survey. Each census team had one person from the village and one CBR volunteer thereby combining

1 See Appendix XVIII

familiarity with the village and a broad understanding of the goals of the survey.

The local community was well prepared for the exercise with publicity in the national newspaper, radio, in schools, health clinics and places of worship and announcements at the local cinema and by the local town crier who walked through the village announcing the survey. The Local Village Health Committee was constantly involved in these preparations and had begun to make plans for a resource unit to meet the needs of the disabled children in the village. It was therefore clearly understood by the participants that the survey was not merely an academic exercise but had an immediate practical purpose . The results of the survey are presented in Tables 5.1 and 5.2

Table 5.1 Results of survey of village community

Number of homes visited	815	
Number of refusals to co-operate	4	
Number of adults surveyed	2864	
Number of children (under 15 ys) surveyed	1780	
Total population of survey	4644	
Number of adults identified as disabled (%)	81	(2.8%)
Number of children identified as disabled	33	(1.9%)
Total number of disabled persons	114	(2.5%)

Table 5.2 Types of disability identified in the children

hearing	8
speech	8
seeing	4
moving	6
fits	1
learning	6
Total	33

As can be seen from Appendix XVIII the questionnaire was very general, eg 'does any person have difficulty in seeing?' The census team was guided to qualify these questions as meaning were the problems severe enough that they impeded the person in daily living.

Initially 38 children were identified as disabled. Each of these children was then visited by the researcher and 5 were found to have only minor problems which could be easily accommodated within the regular school system without any adaptation other than good teaching.

A random sample of 30 homes where no disabled person was identified was also visited by the researcher, however no new cases were discovered.

The overall disability figure of 2.5% is slightly lower than the 3.9% figure reported by Tauber(1981) based on house to house surveys in six areas of Guyana.

The researcher is confident that the figure of 33 children (ie 1.9% of the child population of the village) is an accurate estimate of the minimum need within the community for some form of special educational provision.

The Chief Education Officer, of the Ministry of Education, requested a meeting with the researcher to discuss the results of the survey and to review possible courses of action. The National Rehabilitation Committee used the survey results as evidence to support their advocacy for the creation of a resource unit in the area.

The survey therefore demonstrated a real need. The community's participation and the response of the Ministry of Education indicated an appreciation of the problem within the country. As the programme continued more and more children were referred to the project and requests were received from other regions of Guyana to run CBR programmes in their areas suggesting that the needs of the disabled will be regarded as a priority once it can be demonstrated that something tangible can be done to help them.

5.3 Is the concept of parental involvement culturally appropriate in a LDC context?

Is the idea of the mother spending X minutes per day teaching the child part of their culture? There may be a danger of a mass export of Western packages to developing peoples, adapting the materials on simplistic levels, rather than questioning what the parent is actually being asked to do. Parent involvement programmes may create the problem of forcing children into moulds and pressuring parents to behave in ways which may be inappropriate for their culture. Parental involvement reflects Western concepts of education and child-rearing. Programmes such as the Portage Project are set in an American culture and demand special equipment and established routines. Families in LDCs often do not have such a routine, controlled life-style. It therefore needs to be examined whether the concepts of education and child-rearing which characterise parental involvement projects are meaningful to a population with a very different cultural background.

At least three pre-requisite skills are necessary to implement a parental involvement programme:

i) understanding of child development: an appreciation that children develop skills in an orderly sequence which is relatively universal.

ii) opportunities for teaching: the acceptance by the parents that changing the enviroment or their approach could help the child learn.

iii) belief in teaching: the belief that child development can be accelerated by intervention and that parents can play a key role in this respect.

An attempt was made to examine the above questions by asking 137 Guyanese mothers to complete a questionnaire [1].

1 See Appendix II

The original questionnaire, developed by Powell and Perkins (1984) was adapted for use in this study. The questionnaire was administered by 12 interviewers trained by the researcher. The concept of ages and stages of child development was further explored in a study of 31 Guyanese mothers. Each of the mothers was given a series of 104 cards; one of the Portage items was written on each card; every 5th item from the original checklist was used for the study. The items were presented in a random order and the mother was asked to sort the cards according to the order in which a child could be expected to acquire the skill.

i) Understanding child development: The mothers had no difficulty with the sorting of the Portage items. The concept of looking at child development in sequence presented no problems. The items were sorted separately according to area (ie Motor, Cognitive, Self-Help, Socialisation and Language).Table 5.3 gives the results of the Spearman correlations with the original Portage developmental sequence.

Table 5.3 Spearman correlations between mothers sorting of Portage items and the original Portage sequence

	Motor	Self-Help	Cognitive	Language	Social
N =	26	31	24	28	28
Range of correlat.	.86 - .96	.70 - .93	.59 - .87	.62 -.94	.64 -.85
Mean correlat.	.93	.85	.73	.78	.77

The results were therefore consistently in accordance with the original Portage development sequence and revealed that mothers did have a conception of the child's development proceeding in stages and that the stages were comparable to Western norms.

The questionnaire asked 137 mothers [1] a series of questions concerning the ages at which children normally acquire certain developmental tasks. Table 5.4 presents the results.

Table 5.4 Mothers' assessments of the ages at which children acquire certain developmental tasks

At what age do child.	Western norm *	Earlier Western norm		Within Western norm		Later Western norm		No response	
		N	%	N	%	N	%	N	%
walk unaided	1-2 ys	42	31%	91	66%	1	1%	3	2%
dress unaided	4-5 ys	78	57%	39	28%	17	12%	3	2%
feed unaided	2-3 ys	29	21%	84	61%	20	14%	4	3%
wash unaided	4-5 ys	35	25%	62	45%	35	25%	5	4%
dry by day	2-2½ ys	27	20%	53	39%	47	34%	11	8%
say words	1 yr	21	15%	48	35%	64	47%	3	2%
sit unsupport.	6-9 mths	20	15%	100	73%	14	10%	3	2%

1 Appendix III gives background information on the respondents to the questionnaire.

* Western norms : Powell and Perkins (1984)

The overall agreement with Western norms was 50%. The disagreement concerning certain ages is perhaps less important than the fact they do appear to share the concept of ages and stages of development. With the exception of the ambiguous question concerning 'becoming dry by day', only 2.5% of the sample overall were unable to offer answers to the questions. The earlier estimates concerning walking, dressing, washing and feeding could reflect the larger mean family size with the need for the child to become independent as early as possible to allow the mother to attend to younger children. By contrast the 47% of the sample who reported later development norms for saying words could reflect the lack of focus by mothers on this aspect of child development.

ii) Belief in teaching: The mothers were asked a series of four questions concerning whether the child could be helped to achieve certain developmental tasks. Table 5.5 presents the results.

Table 5.5 Mothers' assessment of whether children can be helped to achieve developmental tasks

" Can a child be helped to ..."	
walk unaided	82% agree
feed unaided	86% agree
become dry by day	80% agree
say words	96% agree

In each case a number of plausible and realistic teaching suggestions were given to help the child acquire the various skills [1]. Mothers do therefore have the belief that the child can be taught to acquire early developmental skills and that they can play a key role in this process.

1 See Appendix III, Table 6

iii) Opportunity for teaching: 24% of the sample represented single-parents. The fathers' role in the other homes was minimal [1]. The parents were asked concerning a number of house-keeping tasks within the home. 51% of the tasks were done by the mother alone; less than 1% of the roles were performed by the father alone. The burden of the home is clearly on the mothers' shoulders; their ability to put aside specific periods of time to 'teach' the child would need to be considered carefully. Creative ways need to be investigated in which assisting the child's development becomes an integral part of the mother's day rather than making un-realistic extra demands on an already over-burdened individual.

It would therefore appear that the philosophy underlying parental involvement is not alien to Guyanese culture. At the same time real practical constraints are also apparent. Some parents may enthusiastically embrace the teaching role; for others the role is too demanding. It would be valuable to investigate the variables within the child, family and community which contribute to effective programmes.

5.4 The mobilisation of auxiliaries and volunteers from the community

i) Administrative support:

a) Volunteers: The proposal to present CBR as one of the programmes offered by the Institute of Adult and Continuing Education (IACE) received enthusiastic support from the Director of the Institute, who recognised the need for such a programme [2]. The idea of the project complemented the philosophy of IACE, ie to reach out into the rural community

1 See Appendix III, Table 5
2 See Appendix XX for letter of support from Director IACE

and to assist the villagers in becoming more active participants in their own development process. Adoption decisions were taken quickly and unequivocably and the researcher was given considerable freedom in managing the programme.

The vibrant support of the Director of IACE, the early community involvement of the PTA, the excellent media coverage and the unprecedented attendance at the first meeting , ensured a strong foundation for the programme and gave the participants the feeling that they were part of something important and exciting.

b) Nursery teachers: Inevitably the programme took low priority and centrality in the eyes of the Ministry personnel when they were faced with the manifold challenges of the whole educational system. The support of the administration was therefore formal rather than enthusiastic. The programme was regarded as a one-time event rather than an innovative way of meeting pressing needs. The concern was more with the demands which might be made of the administration rather than with any perceived benefits which could be gained. Therefore adopting CBR as a response to local problems was not a salient motive, rather it was regarded as a potential enrichment to the present curriculum for the teachers.

ii) Motivation for participating

Before the training programme began the participants were asked to complete a background information form on themselves. One of the questions asked them to reflect on their reasons for participating on the programme. Table 5.6 presents the information.

Table 5.6 Reasons stated on Background Information Form for participating

Reason	Number of respondents mentioning the item			
	Volunteers N=26		Nursery Trs.N=25	
	N	%	N**	%
concern for children	6	23% *	4	16%
professional development	2	8%		
help disabled children	5	19%	10	40%
serve the community	9	35%		
they have disabled children	2	8%		
gain knowledge	2	8%	5	20%
no reason given			6	24%

a) Volunteers: The major motivation for 9/26 was the desire to be of service to their community. A further 6/26 expressed a concern for children in general. In view of the committment they were expected to make to the project, it was not surprising that all had reasons for participating. Only 2 Volunteers gave professional growth as the motivation, for others career motives emerged later once the programme began to attract local and national attention.

One of the major problems identified by Havelock and Huberman (1977) was the difficulty of recruiting appropriate personnel, the rewards for participating were usually too insignificant especially for programmes conducted in the poorest countries.

* all percentages rounded up
** does not include details from four teachers who did not begin the programme because of maternity leave, transfer or resigination

However for the majority of volunteers in this programme the desire to be of service to the community and help children in general was sufficient motivation to explain their involvement.

b) Nursery teachers: The motivation of the nursery teachers to participate makes a sharp contrast. 6/25 could think of no reason for participating. 10/25 said they wanted 'to help disabled children', possibly because this was presented as one of the major objectives of the programme. 5/25 simply wanted 'more information about the disabled'.

The teachers were presented with a situation they could not easily refuse, their concern lay with the demands the programme would make on them rather than with any perceived merit of the project. There was no evidence of any strongly felt user need, the plan appeared to have some value, it was supported by the administrators, presented by a recognised authority and therefore agreed to in good faith, however they were consumers of the project rather than active agents.

iii) Reaction to implementation of programme

a) Volunteers: 30 persons were accepted for the programme, however in the first two weeks 4 dropped out. Two gave professional committments as their excuse, one left the area and one gave no explanation. Over the 15 mth course of the programme, five more left the programme, three moved, the other two gave no excuse. Of the remainder, 17 made a good start to the programme and soon began working with a disabled child. Two took some months before beginning the practical work and two never did begin the work with the families.

28 visits were made by Independent Evaluators (IEs) to assess the Local Supervisors (LSs) in their work with the child and the family. 16 visits were made to the volunteers and 12 to the nursery LSs.On each visit IE completed an assessment form *. The results of these assessments are summarised in Appendix XXXXIII.

The majority of the volunteers LSs [1] were judged to be highly involved in the task of working with the child. 11/16 of the sessions were rated as 'good' or 'very good' [2]. A clear step by step procedure was adopted by the majority of the Volunteer LS (VLS) in explaining the task to the mother [3]. The VLSs had a clear appreciation of the child's particular disability [4],formed a good rapport with the family in 13/16 cases [5], and formed a good rapport with the child in 12/16 cases [6]. In 11/16 cases the VLS appeared to be confident in the teaching task [7]. The majority of VLSs appreciated that their task was to help the mother to be more effective in their interaction with the child rather than taking full responsibility for the child themselves [8].

In 10/16 cases the IE commented on the patience, organisation, sensitivity or confidence of the VLS as being the most positive feature of the session [9]. In 9/16 cases the IE could think of no negative feature of the training session. In three instances however the IE was concerned by the lack of planning which characterised the session [10]. In 10 cases aids were used in the teaching session, 8 of these were produced by the VLS or by the parents [11].

* See Appendix XVI

1	See	Appendix	XXXXIII	#13	7	See	Appendix	XXXXIII	#5
2	"	"	"	#14	8	"	"	"	#9
3	"	"	"	#12	9	"	"	"	#3
4	"	"	"	#10	10	"	"	"	#4
5	"	"	"	#6a	11	"	"	"	#2
6	"	"	"	#6b					

In the majority of cases (9/16) the teaching materials were regarded to be of an appropriate level of difficulty, whilst in 5 cases they were regarded as inappropriate [1].

The following are some illustrations taken from the assessments made by IEs of the task the VLS presented:

> Mentally Handicapped child. Objective: child identifies whether objects are the same or different. Child presented with two sets of items (2 spoons and 2 shoes). Child shows which are the same. Child succeeds. VLS encourages mother to become involved in the task by making up a game. More items added, VLS holds up one of the items, Mother and child 'race' to find matching article. Child enjoyed session. LS gradually made exercise more demanding.
>
> Physically Handicapped child. Objective of session: Child drinks from cup. LS physically assists child to drink from cup. LS rewards child with praise. Gradually LS encourages child to hold cup on his own. Porridge in cup. Clay moulded around cup making it easier to grasp. LS explains to mother what she is trying to do. Good rapport between LS and mother.
>
> Mentally Handicapped child: Objective of session: use nursery rhymes to learn body parts. LS tries to teach child rhyme using different body parts. Attempts to make it into game. Child soon looses interest. Mother discouraged by poor response and criticises child.

The majority of the volunteers soon became highly involved in the programme and soon identified a disabled child from within their own community who needed assistance. Although the role of LS was clearly demanding, most of the volunteers appeared to understand the task and formed a good working relationship with the parents.

From the beginning of the programme high emphasis was given to establishing a self-sustaining team. The LSs were not allowed to become isolated and met together weekly to discuss anxieties, doubts and to share successes. A sense of belonging emerged from the participants who came to regard the project as their own.

1 See Appendix XXXXIII #8

b) Nursery teachers: The administrators viewed the programme favourably but rather simplistically with no real appreciation of the demands to be made on the teachers in adopting the new approach.

The response of the teachers and administrators is presented in a schematic form in Fig.5.1. The figure is based on data from the field work journals, attendance at sessions, visits to the homes and an assessment of the LSs' involvement by the parents and IE. The following criteria was used in formulating the categories:

Category	Attendance at sessions	Visits to homes	Nursery teachers	
			N	%
++ highly supportive	81%+	fortnightly +	6	21%
+ active involvement	51%-80%	monthly	5	17%
- indifference	30-50%	quaterly	7	24%
- - no participation	< 30%	none	7	24%
* no participation			4	14%

In ambiguous situations, eg where the LS did attend training sessions but did not visit the child, the field work journals of the IEs and researcher were examined along with the diary observations of the LSs.

Examples of each category are:

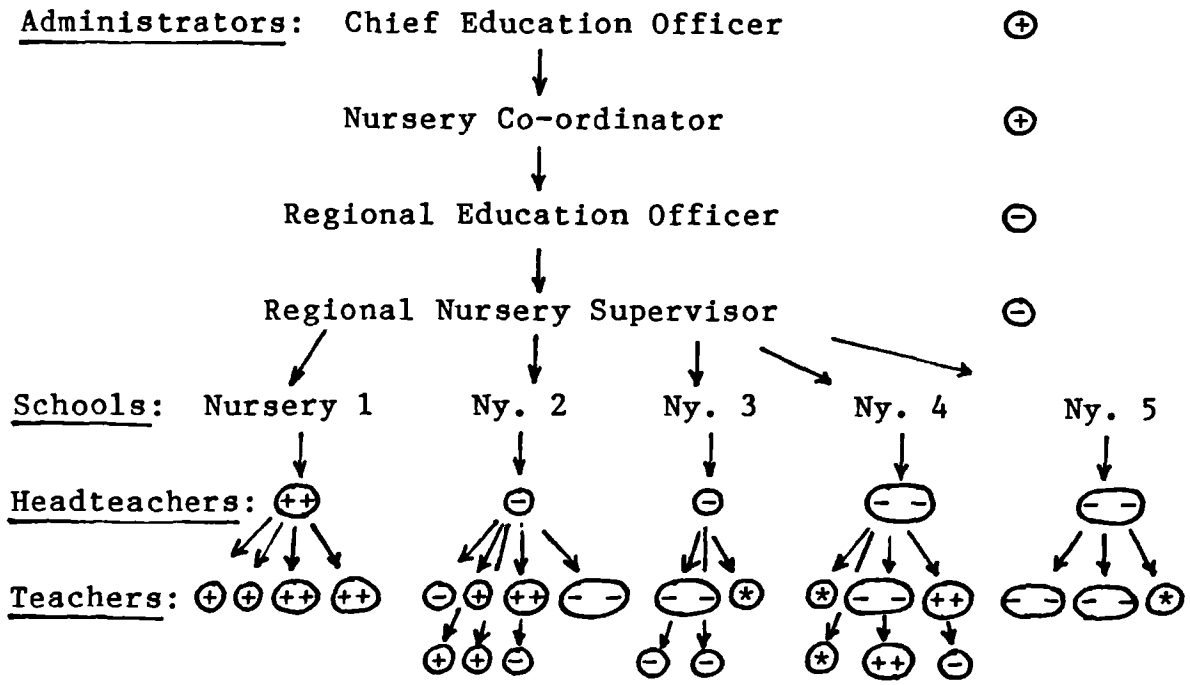
(++) : 'LS visits the home regularly, gets on well with mother and child and has a clear idea how to help the child.' (IE interview of mother)

(+) : 'Mother says LS doesn't come as often as she would like, but when she does visit it is helpful and the child is happy.' (IE field work journal).

(−) : 'Mother has difficulty in rembering when LS visits. Mother is not convinced the LS knows what she is doing when she does visit.' (IE interview of mother)

(− −) : 'Mother finds the interviews and questionnaires meaningless and annoying because there is nothing to evaluate as the LS does not visit the child.' (Researcher's field work journal.)

Figure 5.1 Reaction of Nursery personnel to CBR programme



There was significant variability between sites as Figure 5.1 illustrates. Only one of the nursery heads was highly supportive of the programme. Two of the nursery heads dropped out of the programme (by not attending sessions), one attended infrequently and the other one was pursuing higher studies and was therefore unable to participate fully. When the head of the nursery was committed to the programme the staff were also enthusiastic (cf Ny 1), by contrast in Ny 5 where the Head was not involved, none of the teachers participated in any way in the project.

The IEs made 12 visits to observe the way the Nursery LS (Ny LS) interacted with the child and the family. The IEs were far more critical of the Ny LSs than the Volunteer LSs. 4/12 Ny LS sessions were assessed as either 'poor' or 'very poor indeed', with only 2/12 sessions rated as 'very good' [1]. 5/12 of the Ny LSs were judged as uninvolved in the task [2]. Only 4/12 adopted a clear procedure for the session [3]. 8/12 were regarded as uncertain concerning their role with the child [4]. In 7/12 cases no aids were used [5] and the work that was done was regarded as generally inappropriate [6]. In only three cases was a definite activity prepared for the session [7].

The major criticisms of the sessions included; lack of planning (N=3), lack of sensitivity to child's needs (N=2), little self-confidence (N=2), and little understanding of the task (N=2). In 6 cases the IE gave no description of the task the Ny LS was presenting as nothing was planned.

1 See Appendix XXXXIII #14 p,321
2 " " " #13 p,321
3 " " " #12 p,320
4 " " " # 9 p,320
5 " " " # 2 p,319
6 " " " # 8 p,319
7 " " " # 7 p,320
8 " " " # 3 p,319

The following comments from the IEs' assessment forms are representative of the majority of the sessions with the Ny LSs;

> Deaf child. Objective of session : trace letters. Child given letters of the alphabet to trace following a dot to dot outline. Child soon grew bored with the task and became distracted.
>
> Mentally handicapped child. Objective of session: uncertain Child given a construction toy to play with while LS talked with mother. No clear structure to the session.

It soon became apparent that the majority of the teachers felt overwhelmed; 'so much coming at me at once' as one observed. Despite a series of meetings, individual discussions and field visits by the researcher with the teachers, the programme was nevertheless regarded as complex and unclear and took them away from the relative safety of the school into the perceived uncertainty of the child's home. The majority of teachers were preoccupied with their own concerns, feeling overburdened and poorly paid, whether or not the child was profiting from the experience was of secondary concern. Nevertheless for 6/25 there was a significant level of involvement and demonstrated that for some, especially when the immediate supervisor was enthusiastic, the role is practical.

The active involvement of all five members of staff in Ny1 suggests the key role to be played by the immediate supervisor,in this case the Nursery Head. The Head of Ny1 was keenly interested in the CBR programme from the outset and consistently motivated her staff to take the task seriously. Without her on-going support the researcher feels the four teachers in this nursery may well have shown a similar lack of interest that was generally characteristic of their colleagues in the other four schools.

iv) Inputs on training programme: As can be seen from Table 4.4, p 85, there was a noticeable difference between the training inputs for the two groups in terms of both contact hours and the number and variety of resource persons involved. The 88 hours of contact with the volunteers exceeds the 75 hours training module advocated by Mendis and Nelson (1983). The Nursery teachers' total of 50 hours is obviously far short of the recommended figure. Moreover 84% of the sessions for the nursery teachers were conducted by the researcher alone, as compared with only 36% of the cases for the volunteers. The volunteers also benefited from a greater variety of resource persons. Two of the resource persons who taught on both programmes commented on the volunteers being far more responsive and enthusiastic.

Once the LSs began working with the children, the volunteers were keen for additional training sessions to learn more about the specific needs of the children they were assisting. As a group the nursery teachers were keenly aware that only a specified period each week had been allocated to the CBR training and this should not be increased. Some of the volunteer LSs independently approached professional therapists for teaching ideas for their clients, the same enthusiasm was not matched by the nursery LSs.

5.5 Effect of programme on the children

i) Portage assessments

An extended baseline was established for each child, once a measure of stability was seen in the baseline the LS selected one of the Portage subskill areas to begin teaching. Measurement continued on the other skill areas providing an extended baseline against which to judge the effectiveness of the treatment. Once a noticeable effect was seen in the area in

which teaching was focussed a new area was selected. The data was analysed by visual inspection. The decision rules for judging the significance of an effect need to be made explicit:

a) **Trend direction**: A change in direction towards improvement needs to be observed over phase changes. If improvement is seen an * is printed in column i of Table 5.7, if there is no improvement the column is left blank.

b) **Trend stability**: Changes in trend direction should conform to a 15% stability criterion. The criterion is that stability should be seen in the data in both baseline (A) and treatment (B) conditions. If 85% of the data points in both A and B fall within the stability range an * is printed in column ii of Table 5.7.

c) **Level changes**: Observations are made to see if there is a change in level at the point of introducing the treatment. The scores on the last day of A and the first day of B are noted. If an improvement is seen at the point of introducing the treatment an * is printed in column iii of Table 5.7.

d) **Absolute change of level**: A note is made of the magnitude of the change between the end of A and the end of B. The criterion is that there should be improvement across conditions, if so, an * is printed in column iv of Table 5.7.

e) **Percentage of overlap**: The criterion is that the percentage of overlap between A and B should be less than 5%, if this is so an * is printed in column v of Table 5.7.

The data is summarised in Table 5.7 for the volunteers and Table 5.8 for the nursery school teachers. In this study for treatment to be considered significant four of the preceding five conditions had to be satisfied. The detailed presentation of the raw data for each of these conditions is presented in Appendix XXX1.

Table 5.7 N=1 analysis of Portage scores for children working with volunteers

Child	Portage Area	i)change in trend direction	ii)change in trend stability	iii)change in level	iv)absolute change in level	v) % of overlap	signif
2a	M	*	*	*	*	*	*
	Soc	*	*	*	*	*	*
2b	S/H	*	*	*	*	*	*
3a	L	*	*	*	*	*	*
	Soc		*	*	*	*	*
4a	S/H	*	*	*	*	*	*
5a	Cog		*	*	*	*	*
	Soc		*		*	*	
6a	L	*	*	*	*	*	*
	Soc		*		*	*	*
8a	Soc		*		*	*	
8b	L		*	*	*	*	*
9a	M		*	*	*	*	*
10a	L		*	*	*	*	*
10b	Cog		*	*	*	*	*
11	M	*	*				
12a	Cog	*	*	*	*	*	*
13b	Soc	*	*	*	*	*	*
	Cog		*	*	*	*	*
14a	L		*	*	*	*	*
	Cog		*	*	*	*	*
15a	Cog		*	*	*	*	*
	M		*	*	*	*	*
18a	L		*	*	*	*	*
	Soc		*		*	*	
19a	L		*	*	*		
19b	Cog		*	*	*	*	*
22a	L	*	*	*	*	*	*
	Cog		*		*	*	
26a	Soc		*		*	*	
30a	M	*	*	*	*	*	*
	S/H		*	*	*	*	*
30b	M		*	*	*	*	*
	Cog		*	*	*	*	*
31a	Cog		*	*	*	*	*
	Soc		*	*	*	*	*

Table 5.8 N=1 analysis of Portage scores for children working with Nursery Teachers

Child	Portage Area	i)change in trend direction	ii)change in trend stability	iii)change in level	iv)absolute change in level	v) % of overlap	signif
32	L		*	*	*	*	*
	Soc		*	*	*	*	*
33	Cog	*	*	*	*	*	*
	S/H		*		*	*	
34	L		*	*	*	*	*
	Cog		*	*	*	*	*
35	L		*	*	*	*	*
	Cog		*	*	*	*	*
36	L		*	*	*	*	*
	Cog		*	*	*	*	*
38	Cog		*	*	*	*	*
	Soc		*	*	*	*	*
39	L		*	*	*	*	*
	Soc		*		*	*	
40	L		*	*	*	*	*
	Cog		*	*	*	*	*
43	L		*	*	*	*	*
	Cog		*		*	*	
52a	Cog		*	*	*		
52b	Cog		*	*	*	*	*
	Soc		*	*	*	*	*
54	Cog		*	*	*	*	*
55	L		*			*	
58	L		*	*	*	*	*

M: Motor Soc: Socialisation S/H: Self Help L: Language Cog: Cognitive

According to the criterion of success established here, ie the satisfaction of four of the five conditions, the overall success rate was 77%; for the volunteers the figure was 76% and for nursery teachers 79%. However it should be noted that these results are based only on children who completed the training programme. A more accurate appraisal of the potential of CBR would be to examine the 'success' overall ie including all the cases where the LS embarked on the CBR programme. This would include 2 cases for the volunteers where the LS never began the task of working with the child and 11 cases for the nursery teachers where there was no participation on the part of the LS. When this data is included the volunteers were still effective in 71% of the cases , however the effectiveness of the nursery sample dropped to 53%. The volunteers were therefore more consistent in the LS task than the nursery teachers.

The effectiveness of CBR when the LS does become involved in the programme is illustrated by Table 5.9 which compares the number of Portage Checklist items acquired under treatment and baseline conditions.

Table 5.9 Portage Checklist items acquired per month, per subtest

Portage area	Overall			Volunteer			Nursery		
	A	B	C	A	B	C	A	B	C
Socialisation	.59	1.69	1.06	.64	1.51	.88	.54	1.86	1.24
Motor	.76	2.44	1.16	.82	2.44	1.17	.70	N/A	1.14
Self Help	.71	1.58	.99	.69	1.83	.91	.73	1.33	1.06
Cognitive	.67	1.94	.99	.57	1.96	1.02	.77	1.92	.95
Language	.60	2.10	.89	.47	2.06	.89	.72	2.14	.89
Mean	.67	1.95	1.02	.64	1.98	.97	.69	1.91	1.05

A: Baseline B: Treatment C: 6 month follow-up

Table 5.9 therefore presents persuasive evidence of the value of the CBR approach in assisting in the child's development by contrasting the respective gains in the baseline (A) and treatment (B) conditions. The gains recorded under treatment conditions are continued, although in a more moderate fashion in the 6 month follow-up study.

Table 5.10 presents information on the progress recorded in the different Portage areas according to the criteria of success established on pages 96-98.

Table 5.10 Effectiveness of treatment according to Portage subtest

	Frequency each area was selected			Frequency interv-vention effective			Overall success
	Total	Vol	Ny	Total	Vol	Ny	
Motor	6	6		5/6	5/6		83%
Socialisation	15	10	5	8/15	4/10	4/5	53%
Self-Help	5	3	2	4/5	3/3	1/2	80%
Cognitive	19	11	8	16/19	10/11	6/8	84%
Language	18	8	10	16/18	7/8	9/10	89%

The range of effectiveness for four of the Portage subtest areas was consistently high, ranging from 80% to 89% success. The only area where success was less noticeable was Socialisation where the intervention was only effective in 53% of the cases.

Whilst the overall results are persuasive concerning the value of CBR as assessed by the Portage Checklist it should be appreciated that the Portage Checklist is not a fixed scale. The Portage items are not evenly separated, a gain of eg 4 in

one scale may not be comparable to a gain of 4 items in another scale. Nevertheless it is felt that the results consistently indicate the value of the treatment that was introduced.

ii) Griffiths assessment:

The Griffiths Test of Mental Development was administered at the beginning of the programme before training began, at the end of the 15 month programme and again 6 months later as a follow-up exercise. the raw data of the Griffiths assessments is presented in Appendix XXIX.

The results of the Griffiths assessments are presented in Table 5.11. The results of t test analysis for each of the subtests, pre and post training and 6 months after completion of the programme are presented.

Table 5.11 Results of Griffiths assessments
Volunteers

Griffiths Subtest	Pre-Test Mean	SD	Post-Test Mean	SD	Follow-Up Mean	SD	Pre/Post t	Pre/FU t
A	63.2	27.0	64.3	27.1	69.7	27.8	4.57 **	2.84 *
B	62.7	23.6	63.7	23.2	67.7	22.5	1.30	2.03
C	42.0	26.5	42.3	25.7	46.8	27.2	1.17	2.40 *
D	54.6	22.8	57.0	21.3	59.1	21.5	2.66 *	1.30
E	49.3	21.8	53.3	20.2	53.9	23.0	4.09 **	4.34 **
F	49.3	21.8	51.2	22.4	53.9	23.0	1.73	1.98
GQ	53.6	19.7	55.3	18.9	59.3	19.2	4.07 **	5.37 **
Nursery								
A	93.0	20.7	91.8	12.8	95.2	15.9	.53	2.24 *
B	80.9	15.5	84.2	11.1	93.9	12.0	2.01	3.85 **
C	60.2	22.7	66.7	23.6	67.4	24.2	2.11	2.19 *
D	75.0	14.6	79.6	12.8	85.9	16.1	3.43 **	3.96 **
E	68.0	12.7	71.1	13.5	70.6	14.0	2.34 *	.94
F	67.9	18.3	74.3	16.5	73.2	19.0	2.02	.61
GQ	74.2	11.3	77.7	10.8	81.1	12.6	3.95 **	4.20 **

* sig at .05 level ** sig at .01 level

A: Movement B: Social C: Hearing D: Eye-Hand co-ord.
E: Performance GQ: General Quotient

A repeated t test of the results pre and post training was significant for both volunteer and nursery samples at the .01 level on a two tailed test. These gains also remained significant over the six month follow-up. The gains were more appreciable for the volunteer than the nursery group, however both groups recorded significant improvements.

The Griffiths Test includes a few items which are dependent on parental report, it could be argued therefore that mothers may simply be observing the child more keenly by the end of the training programme. However a statistically significant change was also evident on the Performance Scale, which is objectively assessed, suggesting that the other improvements are real.

iii) Assessments made by independent evaluators (IE)

The IEs were trained special education teachers. They performed a number of functions. In the first four months of the programme a total of 61 visits were made by the IEs to assess children on the Portage test to verify the LS's evaluation of the child's development. All the families were visited by the IEs to carry out a battery of questionnaires and interviews at the beginning of the project and again, 15 months later, at the end of the programme. All the families were again contacted 6 months later to carry out follow-up questionnaires. In addition a total of 28 visits were made by the IEs to assess the quality of the interaction between the LSs and the parents of the child [1]. The IEs were therefore well placed to make an evaluation of the child's progress.

1 See Appendix XXXXIII

The IEs kept an on-going field work journal in which they noted key points each time they visited the family. This material along with the formal evaluations IEs made of the LSs [1] formed the basis of the assessment made by IE of the child's progress. At the end of the 15 month programme the IE was asked to rate the child's improvement using the following checklist:

i) **marked improvement**: child shows marked progress in a number of areas, improvements which are noted by other family members

ii) **moderate improvement**: signs of improvement evident in some areas

iii) **little improvement**: some slight signs of progress evident

iv) **no improvement**: no real progress seen in child's development
   a) no improvement: LS involved: LS visited > monthly
   b) no improvement: LS not involved: LS visited < monthly

v) **no participation**: LS never began working with the child

The mothers were also asked by the IE concerning their level of education and the combined family income. The level of involvement of the parents was assessed by the researcher according to the following criterion:

i) **deeply involved**: parents attended CBR training sessions regularly (ie monthly), involved in the creation of the Unit for disabled children and attended public awareness exercises

ii) **involved**: parents attended an occasional CBR training session

iii) **limited involvement**: parents occasionally left the home during the visit of the LS and showed little interest in the programme

iv) **no involvement**: parents did not take part in the programme either because of disinterest or because of other pressing concerns

1 See Appendix XVI

The seriousness of the child's disability was jointly assessed by the two co-ordinators of the programme along with an analysis of the child's Griffiths scores.

The child's progress was then assessed in the light of the nature and severity of the disability, the socio-economic and educational level of the parents and the level of involvement of the parents. The results are presented in Tables 5. 12 to 5. 17 and analysed using Chi square. As the numbers in each cell was small the data for 'marked' and 'moderate' improvement and 'little' or 'no' improvement were combined together. The results of the analysis are presented after each Table.

Table 5. 12 Assessments made by Independent Evaluators

	Total N=53		Volunteers N=27		Nursery N=26	
Assessments	N	%	N	%	N	%
Marked improvements	13	25%	7	26%	6	23%
Moderate improvements	6	11%	3	11%	3	12%
Little improvement	6	11%	4	15%	2	8%
No improve.: LS involved	8	15%	5	19%	3	12%
No improve.: LS not involved	7	13%	2	7%	5	19%
No participation	9	17%	2	7%	7	27%
Other reasons	4	8%	4	15%		

Table 5. 13 Progress according to type of disability

	N=39	marked/moderate		little/none	
		N	%	N	%
Mental Retardation	19	9	47%	10	53%
Deaf	3	1	33%	2	67%
Physically H/C	8	6	75%	2	25%
Speech	6	2	33%	4	67%
Undiagnosed	3	1	33%	2	67%

χ^2 = 3.36, 4 df, not sig

Table 5. 14 Progress according to seriousness of disability

	N=39	marked/moderate		little/none	
		N	%	N	%
severe	20	10	50%	10	50%
moderate	13	6	46%	7	54%
mild	6	3	50%	3	50%

χ^2 = 0.04, 2 df, not sig

Table 5. 15 Progress according to level of involvement of parent

	N=39	marked/moderate		little/none	
		N	%	N	%
deeply involved	5	5	100%		
involved	13	11	85%	2	15%
limited involvement	16	2	13%	14	87%
no involvement	5	1	20%	4	80%

χ^2 = 22.02, 3 df, sig at .01 level

Table 5.16 Progress according to level of mothers' education

	N=39	marked/moderate		little/none	
		N	%	N	%
primary	33	17	52%	16	48%
secondary	6	2	33%	4	67%

χ^2= 0.67, 1 df, not sig

Table 5. 17 Progress according to parents' income

	N=39	marked/moderate		little/none	
		N	%	N	%
< G$600	12	7	59%	5	41%
601 - 1500	21	10	48%	11	52%
1500 +	6	2	13%	4	87%

χ^2= 1.02, 2 df. not sig

The results of the volunteers are consistently better than the nursery teachers. 14/26 of the volunteers sample showed some progress as compared with 11/25 of the nursery group. 12/25 of the teachers were not involved in the programme whilst only 4/26 of the volunteers did not begin working with the child.

Table 5. 13 illustrates that the most consistent progress was made by the physically handicapped children, with 6/8 of the children showing marked/moderate improvement. The results for the mentally handicapped children were fairly evenly divided between the four categories of progress. The other samples are very small although they suggest that children with speech problems and deaf children may need more intensive help than is offered by this programme.

Table 5. 14 suggests that the degree of progress seen is not related to the degree of impairment. Table 5. 16 also suggests that progress is not dependent on the educational level of the mother and Table 5. 17 indicates that financial resources are not an over-riding consideration. It is not surprising however that Table 5. 15 reveals the most noticeable results showing a clear relationship between the degree of parental involvement and progress seen in the child. The crucial consideration therefore appears to be the parents' desire to help their child, with the most involved parents achieving the most noticeable gains in their children.

A total of 28 visits were made by IEs to assess the quality of the interaction between the LS and the family. The IEs' assessments were also used to analyse the relationship between the professional, educational and financial backgrounds of the LSs and the progress recorded by the children they worked with. Tables 5. 18 to 5. 20 analyse these interactions.

Table 5. 18 Child's progress according to educational background of LS

	N=28	marked/moderate		little/none	
		N	%	N	%
primary	5	2	40%	3	60%
secondary	14	8	57%	6	43%
tertiary	9	5	56%	4	44%

$\chi^2 = 0.43$, 2 df, not sig

Table 5. 19 Child's progress according to professional background of LS

	N=28	marked/moderate		little/none	
		N	%	N	%
medical background	4	3	75%	1	25%
educational					
i) trained	9	5	56%	4	44%
ii) untrained	10	5	50%	5	50%
non-professional	5	3	60%	2	40%

$\chi^2 = 0.74$, 3 df, not sig

Table 5. 20 Child's progress according to financial background of LS

	N=28	marked/moderate		little/none	
		N	%	N	%
< G$700	17	10	59%	7	41%
> G4701	11	6	55%	5	45%

$\chi^2 = 0.04$, 1 df, not sig

The child's progress, as assessed by the IEs, did not appear to be influenced by the educational, professional or financial background of the LS. The data in Table 5. 19 suggests that a health background may be advantageous, however the cell size is too small to form definite conclusions. No simple conclusions can therefore be offered regarding the determining factors of the effectiveness of a LS.

iv) Assessments made by mothers [1]

The following are the key findings:

a) evaluation of programme:

* the unanimous feeling of the mothers at both the post-training and follow-up interviews was a desire for the programme to be continued [2]. Typical comments included:

> the programme should reach the whole of Guyana, it's given me very different feelings towards my child... most parents in this situation feel nothing can be done, this programme has helped change some of these ideas [3].

* 17/20 Volunteer Mothers (VM) and 13/18 Nursery Mothers (NM) found the programme 'very helpful', the remainder found it 'quite helpful' [4].

* 14/20 VM and 11/18 NM said the programme focused on the issues they were concerned about at the outset of the project [5].

* the 6 month follow-up interview highlighted some of the contrasts between the two programmes for volunteers and teachers. When invited to comment on any low points of the project 14/16 VM offered no criticisms, by contrast 6/14 NM complained that the LS did not visit her regularly [6].

1 The following abbreviations are used in referring to the assessment devices adopted in the programme

	Vol	Ny	Reference
Pre: Pre Training Interview	N=26	N=23	Appendix XXVI
Post: Post Training Interview	20	18	Appendix XXVII
F/U: Follow Up Interview	16	14	Appendix XXVIII
S/C: Sentence Completion Questionn.	26	23	Appendix XXV

The number following the abbreviation refers to the item in the questionnaire, and page in the Appendix where the raw data can be located.

2 Post #26,p 292
3 F/U #10,p 294
4 Post #27,p 292
5 Post #2,p 288
6 F/U #3,p 293

One mother commented:

> the LS only comes to ask questions, there were no improvements because the LS didn't do anything, I don't know what's going on with this programme.

b) evaluation of child's progress:

* in the 6 months before the programme began 11/26 VM and 8/23 NM had either seen no improvement or a deterioration in the child's condition, the mothers commented:

> no one helps...no one's interested...teachers don't bother with the very slow children [1].

* by the end of the programme all VM and 12/18 NM noted improvements in their children [2], includimg the child being happier (N=3), more independent (N=6), more mobile (N=4), more motivated (N=5), better behaved (N=2) and able to communicate better (N=10) [3].

* a major gain noted by 7/16 VMs in the follow-up interview was the way the programme assisted in integrating the child into the mainstream of society [4].

* 18/20 VM and 13/18 NM commented that others had also observed noticeable changes in the children [5].

Summary: the great majority of parents found the concept of CBR acceptable and desirable, any criticism was more with the lack of visits rather than concern that the LS did not know what they were doing. Complaints were voiced more frequently by the NMs.

1 Pre #12,p 286
2 Post #3a,p 288
3 Post #3b,p 288
4 F/U #2,p 293
5 Post #16,p 290

5.6 Parental involvement

i) Is the role practical?

* before the project began 15/26 VM and 18/23 NM had received no professional help at all for their child [1], the majority of the assistance that was provided was simply medical checkups at the local clinic [2]. Only 6/39 had received any form of rehabilitation for their specific disability[3]. By the end of the programme 9/20 VM and 2/18 NM were referred to specialised agencies through the CBR programme and all were highly satisfied with the results [4].

*at the outset of the programme 19/26 VM and 15/23 NM said they received help from husbands or other family members in caring for the disabled child in the home suggesting that a foundation therefore existed on which to nurture family involvement [5]. By the end of the project only 2/20 VM and 5/18 NM said they never received any assistance from family or friends in helping the child [6]. Whilst the situation therefore improved for the VM it remained relatively unchanged for the NM . This impression was confirmed by the LSs when they were asked if they felt family and friends were any more involved in assisting the child at the end of the programme than before, this was true for 7/13 VM and 9/16 NM [7].

* 18/20 VM and 15/18 NM said the programme did not interfere with their other responsibilities in the home [8], 18/20 VM and 13/18 NM claimed to be able to integrate CBR tasks into their daily routine [9].

1 Pre #6,p 285
2 Pre #7,p 285
3 Pre #6,p 285
4 Post #13,p 290
5 Pre #13,p 286
6 Post #25,p 292
7 LS Inter. #19,p 315
8 Post #10,p 289
9 Post #9,p 289

* 7/20 VM and 8/18 NM spent on average 30 minutes a day or less on the programme, 11/20 VM and 6/18 NM spent over 30 minutes daily [1].

ii) Is the role acceptable?

* in the training high emphasis was placed on the need for tact and caution and the LSs were directed to discuss specific areas in which the child shows some delay rather than making pronouncements on handicapping conditions to the parents. There were only three cases in which the parents refused to become involved in the programme, in these cases the above guidance was disregarded and there was an over-zealous use of diagnostic terms.

* 16/20 VM and 13/18 NM felt they played a major role in the programme, only 1/20 VM and 3/18 NM said they felt uninvolved in the programme [2].

* the acceptability of the role can be reflected by the more structured approach mothers adopted with their children following the training programme. Initially when asked how they would teach a jigsaw task to the child, 12/26 VM and 6/23 NM could offer no response and 14/26 VM and 7/23 NM simply suggested giving a demonstration of the task [3]. Following the programme 7/20 VM and 3/18 NM adopted a combination of physical and verbal prompting with finished examples and feedback. Only 3/20 VM and 2/18 NM failed to offer suggestions in the follow-up interview concerning the jigsaw task [4].

1 Post #9,p 289
2 Post #4,p 289
3 Pre #11,p 285
4 Post #17,p 290

iii) What expectations were there of the programme?

* at the outset none of the parents had a clear idea of what the child's disability entailed. The disability was invariably explained in vague general terms; a deaf child was regarded as 'passionate can't have her own way', a severely mentally handicapped child was thought of as 'a little slow in his development' and a severely cerebral palsied child 'can't walk too properly yet' [1]. 14/26 VM were still confused concerning the causation of the child's disability [2].

* the parents' expectations and hopes for the programme at the outset were vague and general, they were largely unaware of what the child was capable of achieving. 5/23 NM expressed no hopes for the programme reflecting the far more passive role they adopted in comparison with the VM [3].

Summary: some of the critics of parent involvement projects feel that professionals often overlook the many competing demands made on the mothers' time especially in LDCs. However in the majority of cases here the parents welcomed the programme and felt they played key roles in the project. A foundation exists on which parent involvement can be established and such a programme can be effectively integrated into the mothers' daily routine. The approach also helps the parents to gain access to more specialised services.

1 Pre #5,p 284
2 S/c #2,p 281
3 Pre #19,p 287

5.7 Effect of programme on parents' attitudes

i) Reaction to the child:

a) Child Rating Scale [1]: The Child Rating Scale was administered to the mothers pre and post training. Three independent judges rated the items positive or negative, the ratings for the negative items were reversed. The questionnaire gives three indirect measures of the mothers' reaction to their children:

1) ratings of their own child
2) comparison between ratings of own child and the 'ideal' child

and 3) comparison between ratings of own child and the 'average' child

It was felt that the scale would be useful in comparing the parents' assessment of their children in relation to their concept of the ideal child and the average child and to examine how these assessments change as a result of the training programme [2].

The significance of the changes over time was assessed by a repeated t test on the scores for which pre and post test scores were available [3]. The range of possible scores is 17-85, the higher scores reflect more positive attitudes towards the child.Table 5. 21 summarises the t test scores.

1 See Appendix XIV

2 The raw data is presented in the form of a bar chart in Appendix XXXII

3 Five of the volunteer sample were no longer available for the post-test, four moved out of the region, and one died.

Table 5. 21 t test analysis of Child Rating scores pre/post training

	Volunteer (N=20)						Nursery (N=20)					
	own		ideal		most		own		ideal		most	
	pre	post	pre	post	pre	post	pre	post	pre	post	pre	post
X	49.9	62.1	78.1	79.8	55.8	54.4	56.9	61.9	73.3	77.0	56.6	55.2
SD	9.6	5.3	4.0	4.7	4.3	6.4	5.8	5.2	5.5	5.6	3.7	6.6
t	5.21 **		1.33		.74		3.38 **		3.37 **		.94	

** sig at .01 level, 19 df, using a two-tailed test
X: mean SD: Standard Deviation

The following paired t tests were also carried out:

Vol. pre test	: own/ideal	t = 10.45 **
	: own/most	t = 2.41 *
Vol. post test	: own/ideal	t = 12.87 **
	: own/most	t = 5.48 **
Ny. pre test	: own/ideal	t = 9.78 **
	: own/most	t = .20
Ny. post test	: own/ideal	t = 11.33 **
	: own/most	t = 3.18 **

** sig at .01 level
* sig at .05 level

There was no significant difference between the NM rating of their own children and the average child (t = .20, df 19). However the VM initially rated their children significantly less favourably than the average child (t = 2.41, df 19, sig at .05 level). Following the CBR programme however the VM markedly changed their evaluation of their own children to the extent that their ratings were significantly higher than for the average child (t = 5.48, df 19, sig at .01 level). In the

same manner the NM also assessed their children significantly more favourably than the average child following the programme (t = 3.18, df 19, sig at .01 level).

The discrepancy scores between parents' evaluations of their own children and the 'ideal' child, and their own child and the 'average' child were examined. The raw data for the discrepancy scores is presented in the form of a bar chart in Appendix XXXVI.

There was a noticeable decrease in the discrepancy between own/ideal ratings for the VM, the mean score decreased from 28.3 to 17.7. The decrease in the discrepancy between own/ideal ratings for the NM was however very slight, with the mean score remaining almost the same; 16.8 pre and 15.0 post.

The Child Rating Scale therefore suggests that the parents viewed their disabled children more favourably following the CBR programme. The relatively high standard deviation for the assessments made by the VM in the pre test reflects the variability in the parents' attitude towards children with disabilities before the programme began. In the post test the variability was noticeably reduced.

b) Self Rating Scale [1]: The Self Rating Scale was administered pre and post training. The raw data has been transferred to a form for clearer presentation of the results. The Tables give the group means for each question pre and post training.

A repeated t test was found to be significant for both sets of data. For VM t = 8.68, 16 df, sig at .01 level and for NM t = 7.71, 16 df, sig at .01 level.

1 See Appendix XIII

Table 5.22 Self Rating Scale group means of Nursery Mothers' ratings

Item	0 1 2 3 4 5	Group means pre	post	diff
worried		calm	3.0	3.7	0.7
unsure		confident	3.2	4.7	1.5
helpless		in control	3.0	4.0	1.0
depressed re N		happy re N	2.8	3.6	0.8
not enjoying N		enjoying N	3.7	4.3	0.6
no fun with N		have fun with N	3.7	4.6	0.9
uncomfortable with N		comfortable with N	3.7	4.0	0.3
no warmth shown to N		show warmth	3.9	4.7	0.8
ashamed of N		proud of N	3.9	4.9	1.0
unhappy child		happy child	3.9	4.3	0.4
uncertain expectations		clear expectations	2.9	2.5	-0.4
low progress		high progress	3.2	4.2	1.0
pessimistic		optimistic	3.3	4.2	0.9
can't share worries		share worries	3.3	4.4	1.1
no one interested		many interested	3.2	3.9	0.7
afraid ask questions		ask questions	3.6	4.7	1.1
mistrust experts		trust experts	3.5	4.2	0.7

pre: •-----• post: x——x

Table 5.23 Self Rating Scale group means of Volunteer Mothers' ratings

Item	0 1 2 3 4 5		Group means pre	post	diff
worried		calm	2.9	3.8	0.9
unsure		confident	3.7	4.3	0.6
helpless		in control	3.4	4.2	0.8
depressed re N		happy re N	2.2	4.1	1.9
not enjoying N		enjoying N	3.4	4.3	0.9
no fun with N		have fun with N	3.7	4.5	0.8
uncomfortable with N		comfortable with N	3.7	4.4	0.7
no warmth to N		show warmth to N	4.0	4.3	0.3
ashamed of N		proud of N	4.0	4.3	0.3
unhappy child		happy child	3.6	4.5	0.9
uncertain expectations		clear expectations	2.3	4.1	1.8
low progress		high progress	2.4	4.3	1.9
pessimistic		optimistic	2.7	4.0	1.3
can't share worries		share worries	3.2	4.3	1.1
no one interested		many interested	2.7	4.7	2.0
afraid ask questions		ask questions	3.7	4.5	0.8
mistrust experts		trust experts	3.7	4.7	1.0

pre: •-----• post: x——x

The items from the Self Rating Scale which are related were grouped together and the results are presented in Table 5. 24. Both groups of mothers judged their interaction with the child to have changed, feeling more warmth toward the child, enjoying the child's company more and feeling prouder of the child's achievements (Items 5-9). Both groups of mothers also noted the progress the child was making, although this was more noticeable for the VM than the NM (Items 14-17).

Table 5. 24 Summary of related items on the Self Rating Scale

Items	Focus	VM		NM	
		pre	post	pre	post
1- 4	Mother's own feelings	3.1	4.1	3.0	4.0
5- 9	M's interaction with the child	3.2	4.4	3.8	4.5
10-13	M's perception of child's progress	2.8	4.2	3.3	3.8
14-17	M's relationship with others	3.3	4.6	3.4	4.3

c) Questionnaire data: The initial reaction of the mothers to knowledge that the child was disabled was characterised by shock, depression, disbelief, and worry by 18/26 VM and 11/23 NM [1]. When asked at the outset of the programme concerning their feelings towards the child, 23/26 VM expressed sadness, depression and worry [2]. Only 4/26 VM were hopeful concerning the child's future [3], and only 1/26 VM claimed to be highly confident in dealing with the child [4]. 7/26 VM had very little confidence at the outset, commenting:

> when I try to teach her she's so slow to understand ...I get frustrated trying to help her.

1 S/C #4,p 281
2 S/C #1,p 281
3 S/C #15,p 283
4 Pre #9,p 285

By contrast, by the end of the programme, 11/20 VM felt positive toward the child, celebrated the progress the child was making and only 7/20 still expressed worry and concern for the child [1].

One of the mothers reported that previously she regarded her child in terms of what she was unable to do, by contrast, at the end of the programme, the mother looked at what the child could do [2].

By the end of the programme 11/20 VM were hopeful and optimistic regarding the child [3], and only 4/20 VM and 4/18 NM admitted uncertainty concerning the future [4]. 5/16 VM and 6/14 NM felt more relaxed towards the child following the programme [5]. They commented:

> before, I always wondered if he would always be like this, now I feel very relieved because of the improvements I've seen...I used to feel down-spirited now I feel more at ease [5].

In the follow-up interview the mothers were asked, what, if anything, they had learned from the programme which had carried over into their lives following the course, 3/16 VM and 3/14 NM claimed they had learned not to get depressed, one commented:

> I've learnt a lot, most important, I've learnt how to learn, I've learnt how to deal with my child better, now I feel I understand his problem [6].

After the project 15/20 VM and 14/18 NM expressed feelings of high confidence in dealing with their children, none of the parents reported a lack on confidence in working with their children [7].

1 S/C #1,p 281
2 S/C #1,p 281
3 S/C #15,p 283
4 Post #22,p 291
5 F/U #6,p 293
6 F/U #8,p 294

These sentiments of increased confidence were illustrated in the follow-up interview in response to the question, 'what, if anything, have you gained from the programme?' 7/16 VM and 7/14 NM claimed they had new ideas about how to help the child. 2/16 VM and 2/14 NM felt they now had more realistic expectations of the child, and 2/16 VM and 1/14 NM thought they had gained increased patience through the project [1]. A number of mothers now felt they could be of assistance to other parents in comparable situations [2].

ii) Reactions to self

The Malaise Inventory [3] was completed by the mothers pre and post the course and the results are presented in table 5. 25.

Table 5.25 t-test analysis of Malaise Inventory scores

		pretest		post test		
	N	mean	S.D.	mean	S.D.	t
VM	22	7	2.76	3.77	2.75	4.38 **
NM	21	7.09	4.8	4.76	2.70	2.56 *

** sig .01 level * sig .05 level

A repeated measures t test revealed significant changes in attitude for VM (at the .01 level) and NM (at the .05 level) with both groups reporting noticeably less anxiety and depression following the programme.

1 F/U #5,p 293
2 F/U #8,p 294
3 See Appendix XII

The Self Rating Scale also reflects these changes [1]. The analysis over the course of the project reveals a noticeable improvement in terms of the mothers becoming calmer, more confident, feeling more in control and happier towards the child.

The changes, reported by the mothers, were supported by the LSs' evaluations given to the IE where the LSs consistently reported observing:

> greater interest on the part of the mothers, increased concern, greater acceptance and increased knowledge about how to handle the child [2].

Once again, however, the changes are more apparent for the VM than the NM. All of the VM saw changes in themselves as a result of the programme, feeling more relaxed (N=6), happier (N=4), more confident (N=2), more considerate towards the child (N=2) and more aware of how to deal with the child (N=1). By contrast 5/18 NM felt no changes had come about as a result of the programme and 4/18 gave no response to the question (Post #3b). The other 9/18 NM however felt more relaxed, happier and confident

iii) Changed relationship with others

a) Expectations of family members: Before training the conception of how other members of the family could assist with the child were vague and general on the part of 10/26 VM and 3/23 NM, typical comments were:

> they should help in whatever way they can... give advice...teach the child what he cannot do...show kindness. [3]

1 See Table 5. 24, items 1-4
2 LS Int #17,p 315
3 Pre #14,p 286

Following the programme the expectations were far more definite, including help in; dressing and bathing (N=3), playing with the child (N=6), speech training (N=4), and specific teaching assignments (N=15) [1].

b) Perceptions of attitudes in the community: Initially when asked how people in the community react once they know the parents had a disabled child, 12/26 VM and 14/23 NM had negative experiences, including such comments as:

> they shun you...they feel having a handicapped child is like committing a serious offence... they gossip about it.

By the end of the programme the number reporting this experience dropped to 7/20 VM and 10/20 NM. Moreover the number of mothers who felt people in the community were helpful and supportive increased from 10 to 17 following the project [2]. The same change is reflected in the mother's response to the question, 'how free do you feel to discuss your child with your neighbours?' At the beginning 13/26 VM were emphatic they would not do this for fear of ridicule, by the end of the project only 2/20 felt this way. The number of VM who felt quite free to discuss the matter rose from 8/26 to 13/20 following the programme [3].

Before the programme began 13/26 VM and 11/23 NM had never made contact with other parents of disabled children, they had 'never thought about it' or were 'afraid of what people would say'. These numbers decreased to 4/20 VM and 7/18 NM following the project. Of those who did contact other parents 8/14 VM and 5/8 NM found the meeting of great value, commenting:

> I'm now less upset knowing I'm not the only one with these problems...it made me feel good that I had ideas I could share with others...gave me more confidence to take the child out more [4].

1 Post #19,p 291
2 S/C #13,p 283
3 S/C #14,p 283
4 Pre #16,p 286 Post #18,p 291

c) Expectations of the role the community could play: Before the programme began 15/26 VM and 13/23 NM could think of no specific way in which the community could assist them, what suggestions were offered were vague and general:

> teach parents what to do...give advice...assist the child to understand more...give help in any way...try to get involved...do their best for the handicapped child [1].

However by the end of the project 8/20 VM and 4/18 NM had the clear idea they wanted a unit established in the village to help their children. Another 8/20 VM and 6/18 NM requested help in a specific area of training [2].

The Self Rating data, Table 5. 24, supports these perceived changes. Items 14-17 illustrate that the mothers reported feeling more able to share their worries, more trusting of professionals, more confident of asking questions of the experts and feeling more people were interested in helping their child.

Summary: The mothers therefore report changing over the course of the study in a positive direction. One of the fears expressed in Chapter 2 of making parents feel incompetent in dealing with their children as a result of the intervention programme was not seen. On the contrary the reaction toward the child moved away from one of depression and worry to a more hopeful, optimistic and confident approach where they now felt able to offer support to other parents. The parents' expectations of other family members and the wider community became more definite and articulate. Whilst these changes were characteristic of both groups they were generally more noticeable in the volunteer sample.

1 S/C #12,p 283
2 Post #20,p 291

5.8 Case studies

A series of eleven case studies are presented in the hope of being representative of the total group of children on the CBR project. The children are selected according to the degree of severity of their disability and the level of their parents' and the LSs' involvement in the programme. Attempts were made to select children high and low in each of these categories. Table 5. 26 outlines this information on the eleven children chosen for the case studies.

Table 5. 26 Criterion for selecting children for case studies

Parental involvement	LS involvement	Severity of disability	Volunteer NO.	H/C	Nursery No.	H/C
high	high	high	1	Phy H/C	7	MR/Ep
high	high	low	2	Phy H/C	8	MR
high	low	high	3	Multiply	9	MR
high	low	low	4	MR		
low	high	high	5	MR/Ep	10	MR
low	high	low				
low	low	high	6	Deaf	11	Deaf
low	low	low				

Phy H/C: Physically Handicapped
MR: Mental Retardation
MR/Ep: Mental Retardation and epilepsy

In analysing the individual case studies an attempt has been made to examine general themes which run throughout the project, these issues are analysed in more depth after the case studies drawing on additional information from the other children in the programme.

Child 1:

S, four years old, was born with Club Feet. He was a full-term baby born by cesearian section. All the early developmental milestones were delayed. Although he hears, his vocabulary is limited to about 15 indistinct words. At the beginning of the project S spent all his time lying on his back, everything was done for him. He only used a feeding bottle and his diet was based on porridge and milk. His teeth were badly decayed and were no more than a series of stumps. He was neglected by his parents who subsequently separated. The child was assessed as malnourished at 6 months and 'adopted' by his Grandfather who has since provided a loving and caring background.

The Grandfather is a cane cutter who supplements his modest income with gardening. They live in a simple three bedroom wooden house. The Grandfather became one of the most active participants in the programme, attending many of the CBR training sessions, becoming a vibrant member of the Village Health Committee and the National Rehabilitation Committee and constituting one of the most articulate voices for the creation of a unit for the disabled children in the village. Following the first visit to the home by the researcher the Grandfather was making puzzles and jigsaws based on the ideas he observed from the assessment battery.

The LS working with S was a 27 year old district nurse who was known and respected throughout the community. She proved to be a sincere, devoted young lady. Although she had two young children of her own and a demanding full-time job she missed very few of the weekly lecture sessions and subsequently visited S on an almost weekly basis. She established an excellent rapport with the family and at one of the open meetings it was touching to see the LS with S in her arms with the Grandfather sitting next to her.

One of the early problems the LS encountered was S's difficulty with motions, he was unsure of the potty and refused to use it. The LS gave the family the idea of building a simple chair with a table and a hole in the seat. By the next visit the Grandfather had built the chair with the help of a local carpenter and the problem was significantly eased. This early success noticeably increased the credibility of the LS; the child could now sit without constant support, the table encouraged the child to play with things placed in front of him and helped S to feed himself. The chair was often placed on the balcony which allowed S to watch people passing and helped him to become part of the community, it was therefore no surprise that the LS felt able to record in her diary; '...my parents are well pleased with the advice I gave them.'

The early assessment revealed S's keen interest in jigsaw-type tasks and the Aunt was soon busy making simple games which S could assemble at his desk. This early stimulation was no doubt responsible for the gains recorded in the social and cognitive sections of the Portage test. Gains which were also recorded in the Personal-Social Scale of the Griffiths Test. Continued progress in these areas was also evident in the 6 month follow-up assessment [See graph p 322].

The LS gave advice on diet and dental hygiene, introducing the child to a feeding cup and spoon and encouraged the family to look beyond the child's early resistance to the change from the bottle. Gradually S grew accustomed to his new diet and began to eat with a cup and a spoon at his own table. The child was taken to the dentist for the first time.

Some of the wasteful walls which separated the child from the local community were broken down with visits to the zoo and the local park. S took part in the workshop organised by the CBR participants in the first summer of the programme.

The LS introduced the family, through the co-ordinator of the project, to the rehabilitation services in the capital. On one visit the researcher arrived to see the child with a pair of John Thomas boots which had been given by a physiotherapist to correct the curvature of the feet. However the boots had been discarded and the connecting rod which joined the two boots had been sawn off because they were 'too cumbersome'. This incident illustrates the gulf which exists between the specialised IBR facilities in the capital and the experience of the villager. Even a simple device was rendered useless because of the lack of guidance concerning how and why they should be used.

Initially the family wanted to focus on the areas of language and movement, however it was felt by the researcher that success, in the short term, was more feasible in the areas of socialisation and cognitive development. However once progress was seen in these areas they were referred to an orthopaedic surgeon in the capital who began a series of operations to correct the physical deformity.

The physiotherapist helped the family understand the different stages S would have to move through before being able to walk. The father made a walker to help develop the leg muscles and to strengthen the back muscles.

By concentrating on more attainable goals initially the LS was able to help the family reassess the child's potential as the Aunt said at the end of the project;

> we used to look only at what S was not able to do, now thanks to the nurse we're able to see all the things he can do for himself.

Child 2:

D is an example of a child who could be significantly helped by referral to the appropriate IBR facilities in the capital. D is a shy, withdrawn 5 year old boy of moderate intelligence (Griffiths GQ: 79). He suffers from congenital malformations of both legs, possibly caused by rickets, which gives him a bow-legged appearance.

D comes from a very poor family, the mother is not working and there is no father in the home. The house has virtually no furniture and is generally in a state of disrepair. There are no toys or books in the home. D's time is taken up in selling cigarettes from a small stall on the road.

The LS working with D was the local midwife who was known by everyone in the village. The mother was very depressed and discouraged by D's physical appearance, however this was evidently only one of a series of problems which she encountered daily in her struggle for survival. D's mother had not sought specialist help for her son and had not attempted to get the child enrolled in the local nursery as she felt he was 'disabled' in all areas and as such it would be a waste of time.

The LS began to introduce D to simple games and puzzles and gradually penetrated his reserve. At first he showed no interest in exploring the new materials but gradually the LS showed the child what could be done with the shapes and blocks. The LS formed an excellent rapport with the mother and the other family members. The LS showed D's older siblings how simple games could be made out of scrap materials and she soon became a favourite visitor to the home.

In consultation with the co-ordinator, the LS arranged for D to be seen by an Orthopaedic Surgeon who conducted a series of operations to straighten both legs. Initially the mother was very fearful of the operations however sensitive counselling by the LS reassured the mother and D is now mid-way through the series of operations. One leg has already been considerably straightened. Another achievement of the LS was in integrating D into the local nursery school and motivating the mother concerning the value of attending. Before the programme D had not received any help whatsoever for his disability. The LS helped in making the IBR services more accessible to D's family. D now has a place at regular school and there are hopeful signs that he will react positively to the new stimuli and the new challenge [1].

Child 3

At 4 years old C is the third child for the family. The older girls are fit and well, however a younger brother is also showing signs of delayed development. The mother first became concerned at about 8 months when C was not turning over like her earlier babies. These fears were confirmed when other developmental milestones were also missed. C was a difficult child, she seldom smiled, insisted on her own way and was always aggressive and frequently threw temper tantrums.The situation was aggravated by the father being away for long periods working in the interior of the country. The mother's only support was an ageing father who doted on the child.

When she was two years old she began a series of violent fits following a high fever which left her unconscious for 2½ days. According to the mother C regressed to being a baby following these fits.

1 See graph p, 323

C moved about by dragging herself on her bottom. C had no speech and was obviously frustrated by her inability to communicate effectively. The child had previously attended the physiotherapy clinic, however C now proved too heavy for the mother to carry to the sessions. Despite the fact that C came from a relatively affluent background the mother felt unable to take advantage of the specialised facilities which were offered freely only 8 miles away.

Despite her other commitments in the home the mother attended some of the CBR training sessions in the nearby village. The whole family were clearly devoted to C and the mother had earlier sought out the researcher to request that C be included as part of the programme

It was therefore unfortunate that the LS who worked with C was hospitalised with a difficult pregnancy and soon felt unable to maintain contact with the family.

C's home was always immaculate with highly polished floors and a host of ornaments. It was not designed for children. C repeatedly attracted trouble by interfering with the ornaments or playing with the stereo. She became very irritable when restrained. It was often left to the ever patient grandfather to placate the child. Anyone who could not match the grandfather's patience found C a very difficult and demanding child to work with.

The major concern for the parents at the beginning of the programme was to increase C's mobility. The relevant package from the WHO Manual on movement was shared and explained to C's mother along with specific ideas from the Portage Checklist. The mother, a dedicated and devoted lady, was soon integrating some of these suggestions into her daily routine.

Simple games were suggested to alleviate the tedium of C's day. Games which motivated C to move were also introduced. The physiotherapist and the paediatrician met with the mother and explained the necessary stages C would would need to progress through on her path to walking. Initially C would sit with her legs open straight out in front of her, she would not feed herself and would not hold a bottle. To help isolate the fingers C was encouraged to tear up old newspapers. A support seat was devised to help her legs come in to avoid a deformity of the hips. Gradually C learned how to pull herself up with the aid of a poof. She was then encouraged to walk along holding onto the rails of the balcony to move closer to toys placed just out of reach. She also enjoyed looking at herself in the mirror. The mirror was positioned to encourage her to support her weight in gazing in the mirror.

The gains in the Motor area were clearly reflected in both the Portage scores [1] and the Griffiths scores (where the Motor scale recorded a 29 point increase over the 18 month period of the project). By contrast there was very little change in C's performance in other areas.

Both parents felt there had been a significant change in C over the course of the project. Each step C took was a major achievement for the child. Once the mother saw C beginning to walk, she said:

> a year ago, I thought C would be 100% helpless,
> now, I see her starting to move about on her own.

In the six month follow-up C was moving quite well entirely on her own. Her behaviour was noticeably improved, the tantrums were far less frequent and her day was more varied than before. Her speech however showed little change over the course of the project.

1 See graph p, 324

Even when the LS made far fewer visits than was desired, with an intelligent, committed mother such as C's, noticeable improvements were possible by suggesting some simple ideas.

Child 4

H was an 8 year old child who was referred to the CBR programme by her class teacher in a regular primary school because of her lack of progress in school.

H was a very pleasant if rather shy and withdrawn child who was perhaps suffering the effects of a disrupted home life. H proved a difficult child to work with. The LS was from a Negro-Christian background, as such, she had little in common with H who was from an East Indian background.Each evening H attended the local mosque for instruction is Islam and Arabic. The LS soon became discouraged by her inability to find the child at home. The LS also found the home situation unsettling and felt inadequate to deal with the marital problems she encountered. Her solution was to withdraw and visit infrequently.As such, the CBR programme had little influence on H and her family. The graph of the Portage Scores [1] reflect the modest gains that were made over the course of the project. The one area where some progress was seen (ie the motor area) could be the result of an increase in confidence gained by H as a result of the meetings with the LS and the co-ordinators. H always appeared to be very happy with the attention given to her on the occasions when the researcher visited the home.

H's case raises the question of how well equipped a LS is, or can be,to deal with wider social and psychological problems in the home rather than the specific needs of the child.

1 See graph p, 325

The LS in this case clearly did not perceive her role to be that of a social worker and subsequently withdrew from the demands she experienced in the case.

Child 5

M was born 9 years ago weighing 4½ lbs. and was placed in an incubator because of possible anoxia. All the developmental milestones were delayed. He suffers from a right side hemi paresis. His speech is very limited. M is hyperactive never settling on any task for more than a couple of minutes. M assists his mother when he is being dressed. He usually informs his mother when he needs the toilet and then requires help in cleaning himself.

M suffers from grandmal fits as often as three times per day. He was previously on phenobarbitone on doses which the mother, on her own initiative, kept on increasing. M is not on any drug presently. The mother is greatly discouraged by the lack of progress she sees in the child over a period of several years. A paediatrician visited M through the CBR programme and suggested an alternative drug for the fits, however the mother made no attempt to get the drug.

A combination of his daily fits and his frequent bouts of aggressive behaviour led to the child soon being excluded from the local nursery school. M has therefore spent the last several years at home largely deprived of any stimuli. His bizarre behaviour and aggressive manner may be, in part, a reaction to the unstimulating environment he is placed in.

The mother is a single parent, the mother and father having separated several years earlier, in part, according to the mother because of pressures created in looking after M. The LS

who worked with M was a remarkable person. She had no formal education, lived under very modest conditions and yet chose to work with four disabled children on the programme. She had two handicapped children of her own. One was deaf and one was severely mentally handicapped. The mentally handicapped child died during the project under the tragic circumstances of swallowing poison by mistake. Despite the personal tragedy the LS gave very generously of her time and had a natural empathy with the parents.

M proved to be a very demanding child to work with, M's mother had seen no noticeable improvement in the child's condition for years and much of her time was taken in earning a living and managing the home. Despite these very real limitations the LS did record some success in motivating M to tackle jigsaw puzzles and form-board tasks and suggested that more significant gains in the cognitive area would be possible with a more systematic programme reinforced by someone in the child's home. In M's case however the child's disability was only one problem to the mother in a life overfull with difficulties [1].

Child 6

N is a deaf and dumb boy of 6 years old who has never attended any form of school.Because of the difficult economic situation in Guyana, N's parents left to work in neighbouring Suriname 4 years ago. The child was left with the grandparents. Three months after the beginning of the programme the mother returned to Guyana to have a baby.

1 See graph p,326

The situation in N's home was difficult. The grandmother was on the verge of a nervous breakdown as a result of a serious car accident in which her son broke both his legs. N's mother was going through a difficult pregnancy and appeared to have little time for the child. Two months earlier N had set fire to his cousin apparently out of jealousy for the attention he received from other members of the family.

The LS working with N was one of the few men on the programme. He was a single, middle-aged man from a negro background. He worked as a refrigeration mechanic and was active in community affairs in the same village. The LS made arrangements for N to be seen by the Head of the Special School in the capital. The family however never kept the appointment. The LS only learned later that the reason for this was that the grandfather was worried that if his daughter was seen in town with the LS people would gossip. The problem was increased by the fact the family was from a different racial background. Rather than discussing the problem openly the family preferred to miss the appointment, not surprisingly the LS was very discouraged and soon ended his relationship with the family.

This was not therefore a fair test of what could be done through the CBR approach to help a child with profound deafness, however the early assessments [1] suggest this would have proved to be a very demanding challenge.

Child 7

K is a five year old boy who was referred to the programme because of his extremely unsociable behaviour and significant lack of progress at the nursery school. The child began having grand mal epilepsy at one year old and at the beginning of the

1 See graph p, 327

programme he was having fits about 3 or 4 times a day. K's mother visited a series of doctors in the capital with no result. He was on a course of phenobarbitone which , according to the mother was ineffective. The mother therefore decided to increase the dosage with the effect that K appeared to be in a trance-like state.

The mother was candid regarding her despair for the child.She had given up with the drugs and had approached a local mystical religious order in search of assistance. At the beginning of the programme K was a difficult , destructive and aggressive child. On the researcher's first visit to the home, K was tied by the foot to a post with all the furniture and valuables piled on to a table to be out of K's destructive reach. According to the teacher K had never had a fit at school, however he disturbed the teachers with his aggressive behaviour and indecent language. His hyperactivity brought swift beatings in the school.

The LS was a teacher from K's nursery school. She was a sincere and dedicated woman who's own son was also troubled with epilepsy. She therefore could easily understand the torment of the child and the family.Gradually the LS was able to introduce change in the home. A number of simple exercises were suggested to the mother to help develop the child's language ability and stimulate the child intellectually.

About six months after the beginning of the project the parents became Evangelical Christians and felt a profound change had come upon their lives. Whatever reason for the change there was a very dramatic transformation in the child. For the past year K has had no fits, he is completely off the drugs, interacts with others more freely and shows signs of gains in all Portage areas [1].

1 See graph p,328

Child 8

L, a 5½ year old girl, was referred to the programme by her teacher because of her immature speech and lack of progress in school. Her problem was not regarded as serious. L had the physical appearance of a younger child and often acted in an immature way. At the beginning of the programme any question was met with a broad grin. Both her mother and her LS were teachers in her nursery school.

Initially L's speech was difficult to understand and she rarely spoke in sentences. The mother and the LS worked together adapting ideas from the programme to develop her language ability. By the end of the project she was far more integrated in her class and spoke more clearly and in short sentence form. The Portage assessment recorded moderate improvements in the areas of language and cognitive development [1]. She appeared to grow in confidence and learnt to be more independent as indicated in the 16 point gain in the Griffiths in the area of Personal-Social over the 18 month period of the programme.

L therefore was a child with a minor problem who appeared to be helped by the structured approach the project offered. The mother stated she appreciated having an idea of what was a legitimate expectation of the next developmental level for the child.

Child 9

D was an 8 year old mentally handicapped girl who was lost at the back of a regular class in the local primary school. The child would sit at school all day either drawing in her

1 See graph p,329

notebook or day dreaming out of the window. She posed no disruption to the class, having a kind, gentle undemanding nature. She was tolerated by the teacher and the other children. Her classmates did not tease her, instead they tended to ignore her and D would be left to entertain herself lost in a corner.

D came from a very poor background where the parents struggled to do their best on a very modest income. Despite their attempts D is malnourished and appears to be in poor health. Four years ago the mother suffered a nervous breakdown and would appear to be of limited intelligence herself .

The LS who worked with D was a nursery school teacher who had known the family for a number of years. The LS began working with D in an enthusiastic manner at the beginning of the year but married four months later and then had less time to devote to the project.

The lack of visits were unfortunate as the Portage assessment reveals some worthwhile gains in the cognitive area early on in the project [1]. Despite the lack of concentrated help D showed a 12 point improvement on the Griffiths Test over the 18 month period. A noticeable improvement was apparent in the area of Personal-Social development due in part, perhaps to increased confidence generated by the programme.

Child 10

Y, a six year old boy, was referred to the programme by his nursery school teacher who became the LS working with him. Y is a mentally handicapped child with poor health and nutrition. He

1 See graph p,330

missed a good deal of school because of frequent sicknesses. All the developmental milestones were delayed. His speech is still immature and he grasps little of the work in the nursery school. His problems are compounded by frequent asthma attacks. He had very poor visual-motor skills and still has difficulty in holding a pencil.

Y comes from a very poor home. He lives with his grandmother in a one-flat building with another family. The grandmother had little appreciation of the child's difficulties and gave him a series of verbal insults when the researcher attempted to assess the child on the Griffiths Test. The grandmother's attempts to teach the child are futile, she soon grew weary of the task and resorted to berating the child. The grandmother informed the researcher that she had very little faith in the school, it was no surprise to learn therefore that following two or three attempts by the LS to work with Y in his home that the LS resorted to working with the child after school in the nursery rather than the home. Y resented this attention and would frequently ask if he could leave and go home.

The LS working with Y was an older lady who appeared to be genuinely interested in his welfare but was frustrated by the lack of support from the family. The gains in the Cognitive area on the Portage assessment [1] suggests the potential of more intensive help.

Child 11

A is a 6½ year old deaf boy. Until the CBR programme began the child remained at home. Two years ago the mother took the child

1 See graph p,331

to the Special School and was invited to return monthly for parent education sessions. However the mother judged the journey to be too demanding and would have necessitated loosing a day's pay and possibly jeopardising her job. The contact was therefore dropped. The mother was hoping for a place at the school for the deaf, however even if it did become available A would be unlikely to go as the school is not residential and the daily journey would be too arduous and expensive.

A's mother was young and single , most of the child's care-taking was therefore carried out by the grandparents who had little understanding of the nature of the child's disability. The family were directed to the correspondence course offered by the John Tracy Clinic in USA, however the exercises proved too demanding for the grandparents and were therefore hardly used.

The LS working with A was a young single girl who attended few of the CBR training sessions and as such had very little commitment to the programme. She no doubt found working with a profoundly deaf child too demanding and therefore withdrew from the situation, simply making perfunctory monthly visits to assess the child's progress.

The researcher managed to get the child accepted at a local nursery school two days a week despite some resistance from the head teacher. Eventually the child was well accepted by the other children and appeared to enjoy the stimuli and challenge of the new situation. After a few months the child was accepted full time in the nursery and now attends the local primary school on a full time basis. However one wonders how long the child will be able to attend the school before it becomes a boring, punishing experience [1].

1 See graph p,332

Major themes from the case studies

1. Parental involvement

In Chapter 2 some of the literature which suggests parental involvement in LDCs is impractical was reviewed. The lack of involvement of some of the families in this study can be explained by a number of factors:

i) Denial: The majority of cases where the parents were not involved in the project came from the nursery group. Most of the teachers worked with children from their own nursery schools, as a group therefore they were far less disabled than the children in the volunteer sample. For many of the nursery children the lack of progress was not sufficient to merit the concern of the parents. A typical response to a child with speech problems was,'he gan talk when he ready'.

Other mothers felt threatened and defensive, feeling their ability as a guardian was being questioned. Sometimes this uncertainty was tragically projected into aggression against the child. A number of children were regarded as lazy. When the child was unable to complete a task it was not unusual for these mothers to threaten the child with 'lashes'.

ii) Disinterest: Some parents were discouraged by long years without any sign of progress. This was the experience of the families of two Downs Syndrome girls. The low expectations of the parents had been transferred to the children who became moody, aggressive,bored and unrewarding to work with. The frustrations of the girls was channelled into aggression towards other children making their integration a challenging prospect.

iii) Disunity in the home:In at least 5/19 homes where the mother and father were together there was serious disunity in the home, with reports of fights, beatings and frequent separations. Some LSs withdrew feeling ill-equipped to deal with the turmoil of these homes.

iv) Poverty: Poverty was a problem for the single-mothers in particular.In being forced to go out to work the child was often left alone or in the care of an older sibling. One LS reported doing her work sitting on the steps of a neighbour's house, repeated visits never found the mother at home. In such cases there was simply no one available that the LS could work through.

In another family the home was completely bare, the only furniture being one bed. Two children had already died in the home of gastro-enteritis and another child had been injured by being knocked down by a car when unattended in front of his home. A young physically handicapped girl became educated in language and behaviour by her time on the streets. A mentally handicapped boy ate at the home of one Aunt and slept at another. It was often difficult to find him, as none of his 'guardians' knew where he was.

Out of poverty comes ignorance and superstition. Three of the parents resorted to Black Magic in the hope of 'lifting the curse' from their child.

While for some parents the role of involvement was too demanding there were as many others who were deeply involved in the rehabilitation of their children. In one case the father had been tragically paralysed resulting in the mother visiting the hospital daily for the whole duration of the project. Despite this she formed an excellent rapport with the LS and found the time and energy to greatly assist her severely

cerebral palsied child. This was achieved, in no small part, because of the tact, patience and understanding of the LS who repeatedly visited the home and was not dissuaded by often failing to find the mother at home.

A mother was left to care for her multiply handicapped seventeen year old boy without any assistance from any professional source. She had given up her job to care for her child full time. She became actively involved in the project sometimes carrying her son on public transportation to the parents' meetings and , together with the LS, managed to help the youth become more independent, more mobile and more aware of his immediate environment.

Another home of a physically handicapped child was devoid of furniture and life was clearly very difficult for the single parent however she ensured her boy was able to take full advantage of the specialised IBR assistance that the LS organised for her child in the capital.The mother was clearly prepared to make material sacrifices to ensure the child received the help he needed.

At least half of the parents were therefore involved in the programme. It was not unusual to see the parents making teaching aids out of scrap materials for their children. A nucleus of four parents worked tirelessly for the rights of their children. They frequently attended the CBR training sessions for the LSs, they introduced the programme to other parents in the area and created the Village Health Committee which became an articulate voice for the creation of a unit for the disabled children of the village. Two of the parents were subsequently appointed on the National Rehabilitation Committee and met with the Chief Education Officer in making specific plans for the Unit. These two fathers were also instrumental in showing a video on the project in nearby villages and in organising two Summer Workshops for the disabled people in the

area. These two men, from the same village, were a great contrast in styles. One was a cane-cutter with only a few years of education who spoke in' broken' English and the other was an articulate headmaster who was highly respected in the village. Both played major roles in the project and illustrated the fact that everyone had a valued part to play.

2. LS involvement

The volunteer programme was fortunate to draw on the skill and experience of a range of persons from health and education backgrounds, attracting nurses, health visitors, midwives and school teachers. Such people were known and respected within their village communities.

However other persons, with no professional background, were equally as sincere and effective. One of the volunteers had four children , two of whom were handicapped. Despite her problems she worked with four other families with disabled children. What she lacked in formal education she made up in empathy and compassion. Other LSs who were clerks, housewives and students were equally as effective. The dedicated LS who worked with the wife of a crippled husband had no formal qualifications, indeed no schooling could have prepared her with the sincerity and devotion necessary to work with this family who experienced such pain and suffering during the course of the project.

Some of the LSs were remarkably involved in the programme despite the lack of support from the child's family. One of the nursery teachers worked with the daughter of a security guard. The child was left at home in care of a blind grandmother. Despite the lack of support the LS visited the child repeatedly and the shy, isolated and withdrawn girl who refused to speak emerged, through the caring, supportive relationship offered by

the LS, into a normal, lively 5 year old. At the beginning of the programme the LS recorded in her diary,'the other children take pleasure in teasing and bullying her', some months later the LS records an incident where the girl repeated a rhyme for the class and the shock this caused,as 'most of the children were hearing her voice for the first time'.

Another nursery teacher worked with a family with marked marital problems where the wife would frequently run away from the home and seek the support of the LS. In her diary the LS reports repeatedly leaving materials and games for the child, only to return the next week to be informed they were destroyed or lost. Nevertheless the LS continued to visit the home on an almost weekly basis despite attending College herself.

Only about 6/29 of the nursery teachers were highly involved in the project, with 14/29 who either did not participate or who showed no more than passive indifference [1]. This illustrates the gulf between the intellectual rationale of the planners and the reality of the situation. On paper the plan looked excellent. Nursery teachers are employed full time, however the children only attend in the mornings, leaving the teachers technically 'free' in the afternoons. The perceptions of the teachers were very different. The afternoons were given over to the 'planning' necessary for the next day's work. CBR was therefore regarded as a burden to a group of people who felt themselves to be poorly paid .To take on something extra for no remuneration was clearly rather naive in their eyes. This raises fundamental questions regarding how to incorporate CBR into an existing government infrastructure to expand coverage at an economically viable rate. This issue will be analysed in the conclusion.

1 See Fig 5.1,p128

3. Simplified rehabilitation

Very few of the children on the CBR programme had been exposed to IBR facilities before the project began. Of those who had made contact none were able to continue to benefit from the provision at the outset of the CBR programme. Three of the mothers commented quite simply that the child was now too heavy to be carried on public transport. Even though the services were freely available only a few miles away the practical problem of getting the child to the services was too great an obstacle. The other family that had contacted IBR services had left disillusioned by long waits for missed appointments by doctors and specialists. Their attempt to get the child enrolled in a centre for physically handicapped children was thwarted because the child was also deaf and the school had no provision for such children. The school for the deaf on the other hand had no residential facilities.

A number of the children clearly responded to the simplified rehabilitation which the programme offered. The joy on the face of a cerebral palsied boy who is taking a few 'steps' with his legs reinforced with splints made out of rolled-up newspaper and cloth is one of the engaging shots on the video, 'Step by Step' which documented the programme. The modest splints were sufficient to strengthen and support the child's legs. A series of simple exercises helped to stimulate the child's sense of balance. The video shows the boy seated on the arm of a chair, rocking side to side to get the feeling of movement and balance.Simple toys were placed on chairs to stimulate the child to stand up and support himself. After a series of persons had visited her home in connection with the programme the mother turned to her disabled child and said,

> see Portugee, see how you've made this home so special with all these people coming to see us.

A number of the parents began to see what could be used in their everyday environment to help the child acquire the next developmental task. Simple games were suggested to offset the tedium of the day for many of the children with special needs in this rural area.

There were other children who needed more specialised help. The CBR programme was effective in making referrals to such services. In four cases the programme integrated the children into regular schools. Three other children gained places at the excellent special school in the capital. The success of the 'integration' and the relevance of the specialised facilities will be explored in the conclusion.

5.9 Community involvement

An effective innovation needs a well-informed and well-prepared community, a good deal of the time was therefore spent on community awareness. Excellent media coverage in the planning stage, on radio and in the newspaper, did much to enhance the prestige of the programme. The process of community awareness was facilitated by announcements of the programme in schools, shops, clinics and places of worship throughout the area. Subsequent radio programmes, newspaper articles , public meetings and the showing of the video produced by the participants helped nurture the involvement of the community in the project.

Before the programme began the researcher consulted with fellow rehabilitation therapists to discuss programme objectives, to gain their support for the project as resource persons and to begin the process of a two-way referral process between the CBR programme and the traditional IBR facilities within the country. The researcher met, on a number of occasions, with the Parents' Association for Mentally Retarded children, to discuss

the programme objectives and to examine the relevance of the proposed evaluation techniques. The early dialogue with the professionals and parents helped develop a process of local participatory involvement.

The combined effect of the media coverage, the extensive advertising and the support of a local Parent-Teachers' Association laid the foundation for an exciting introductory meeting attended by over 200 persons from the community, 60 of whom requested to participate in the programme. This generated the feeling that to be accepted on the programme was , in itself, something of an achievement.

The opening meeting, chaired by the highly-respected Mayor of the capital city and attended by 80 persons from the community, including prominent rehabilitation therapists, members of the National Rehabilitation Committee and high officials from the University, helped present the project as a joint undertaking.

The Director of the Institute of Adult and Continuing Education gave enthusiastic approval to the project and the researcher was given considerable freedom in planning and directing the programme. Financial support came from the University of Guyana and the University of London and the Canadian International Development Agency. In addition to the financial security this offered it also gave an important psychological boost to the participants in feeling they were part of an important programme funded by a variety of local and overseas agencies.

This early enthusiasm was reinforced by a National Conference organised by the Parents' Association of the mentally retarded, at which the President of Guyana stressed the key role volunteers could play in helping the lives of disabled persons [1]

1 See Appendix XXIII for copy of newspaper article

A good foundation was therefore established on which to develop community involvement. The involvement of key professionals, the participation of the parents' organisations and the support of the National Rehabilitation Committee enhanced the status of the programme, broadened the foundation and warned away potential critics.

The CBR participants ,on their own initiative, organised two, three day workshops for disabled children and their parents. The LSs organised transportation, food, equipment and materials to be donated by a host of local organisations and companies. It proved to be an imaginative and creative use of what was readily available within the community. The workshops focused on demonstrating teaching ideas to the parents and giving children, some for the first time, outings to the zoo and park. Many barriers were broken down in those workshops and a number of parents began to see something of what could be done with their children.

It soon became apparent to the volunteers and the parents that the needs of the disabled children were not being met in the rural areas. A number of children attended the workshop who had never before received help for their special need. A number of parents and community figures organised themselves into a group known as the Village Health Committee (VHC) and became an articulate voice for the hopes and aspirations of the parents of the disabled children in the community. The VHC enthusiastically adopted the CBR programme, played a major role in the area of community involvement and ensured the maintenance and continuity of the project.

The VHC was instrumental in facilitating the integration of four disabled children in the area into regular nursery schools. One of the headteachers commented how eager she was to accept disabled children into her school as she felt this would

be a valuable learning experience for the other children in the school.

A survey, planned jointly by the volunteers and the VHC, was organised to examine the needs within the community. The VHC was highly involved in publicising the survey within the village.Following the survey the results were discussed between the researcher and the VHC and a proposal submitted to the Ministry of Education suggesting the need to create a Unit in the village to meet the needs of the disabled children.

The VHC made all the necessary arrangements for the Unit and secured material help from a wide variety of community resources. The VHC arranged with a local Hindu organisation to use one of the group's premises to house the Unit. The VHC and a group of expatriate women began a series of fund-raising events to raise money and provide the necessary materials for the Unit. The National Rehabilitation Committee (NRC) adopted the findings of the survey and were outspoken in their advocacy for the Unit. Indeed the NRC took the programme as their own and in subsequent meetings with the Ministry of Education they were the ones representing the case of the needs in the village. In one of these meetings the release was secured of a teacher from the Ministry of Education to be responsible for the Unit.

Summary: One of the highlights of the programme was the vibrant involvement of the community and indeed the eventual adoption, by a community group, of responsibility for the project. It should however be noted that the foregoing relates to the work of the volunteers, not of the teachers. This was perhaps the most significant comparison between the two groups. The level of community involvement in the programme facilitated by volunteers was considerable and highly varied, by comparison the teachers were not sufficiently involved in the programme to

generate such enthusiasm and support on the part of the wider community.

The main events of the CBR programme are presented in the following tables, 5.27 to 5.29. Table 5.27 outlines the events which were common to both programmes, Table 5.28 highlights the developments within the nursery programme and Table 5.29 notes the key features of the volunteer project.

Table 5.27 Main events common to both programmes

1. Administrative approval and funding:

   i) Proposal submitted to University of Guyana's Faculty of Education Research and Publishing Committee. Proposal approved and forwarded to University committee for consideration.

   ii) Proposal approved by University of Guyana's Research and Publishing Committee, however because of financial constraints, the University could only pledge 16% of the budget proposal.

   iii) Deputy Vice-Chancellor of the University of Guyana, acting on behalf of the Research and Publishing Committee gave a letter of endorsement for the project to use with an external funding application.

   iv) Canadian International Development Agency approached for funding and grant approved.

2. Foundation established for projects

   i) Researcher met with fellow rehabilitation therapists to discuss the objectives of the programme.

   ii) Researcher met with local Parents' Association of Mentally Retarded Children to seek their support for the programme.

Table 5.28 Main events in Nursery Teachers' project

1. Administrative approval:

   i) Researcher met with Nursery Co-ordinator, project approved.

   ii) Formal proposal submitted to Chief Education Officer (CEO) of Ministry of Education, proposal referred to Research Department.

   iii) Researcher met with Planning Officer of Ministry of Education, proposal supported.

   iv) Project approved by CEO, appropriate regional authorities informed of the project.

   v) Ministry selected 5 nursery schools for the project.

   vi) Researcher met Regional Education Officer for the district identified by the Ministry to work in , approval given for the project.

2. Foundation established for the project:

   i) Researcher met with the head teachers of the 5 nursery schools identified by the Ministry along with Ministry officials to discuss programme objectives, head teachers proved willing to co-operate.

   ii) Researcher held two meetings with all the teachers from the five schools, all agreed to participate.

   iii) Researcher met with the staff of each school separately to discuss the programme, staff responded positively [1].

1 It can be seen that following securing administrative support for the programme there was no further involvement of the community in the nursery project.

Table 5.29 Main events in Volunteers' programme

1. Administrative approval

   i) Proposal accepted by Director of the Institute of Adult and Continuing Education (IACE) of the University of Guyana that CBR be offered as a programme by their institution.

2. Foundation established for project

   i) Researcher met, on several occasions, with a Guyanese Physiotherapist to plan the CBR programme.

   ii) Researcher met with Parent-Teachers' Association of school identified as venue for training programme who in turn mobilised the community.

   iii) Programme advertised in schools, health clinics, places of worship and shops.

   iv) Media coverage in radio and newspaper.

   v) Introductory meeting attended by 200 persons.

   vi) Opening meeting chaired by Mayor of the capital city.

3. Development of the programme

   i) Lectures by rehabilitation therapists from a variety of disciplines.

   ii) Presentations by local Parents' Association of Mentally Retarded Children.

   iii) Beginning of practical work, emergence of a sense of involvement in the project.

   iv) Parents of disabled children from the project begin to attend sessions.

   v) Every 10 weeks evaluation sessions held between LSs and ILSs to assess progress to date.

   vi) Radio programme and newspaper article planned and presented by LSs.

   vii) Panel presentation for local community planned and organised by LSs.

viii) Newspaper and radio publicity prepared by IACE [1].

ix) Speech by Guyana's President stressing the valuable role of the work of the volunteers.

4. Development of community involvement:

i) Three day workshop planned and presented by LSs.

ii) Creation of Village Health Committee (VHC).

iii) Survey of village, planned and executed in collaboration with VHC.

iv) Chief Education Officer proposed a meeting with the researcher to discuss survey findings [2].

v) National Rehabilitation Committee adopted survey results, and in collaboration with VHC, proposed the formation, in the village, of a Unit for children with disabilities. Suggestion presented to Ministry of Education.

vi) Local schools began to accept disabled children into their classes.

vii) Two-way channel of referral developed between IBR and CBR.

viii) Former Prime Minister of Guyana accepted an invitation to be the Guest Speaker at the Graduation. (He later proved unable to attend.)

ix) The presence of the Head of the Special school and the Chairperson of the NRC to distribute the certificates at the Graduation illustrate the support the programme enjoyed from these two key agencies.

x) Production and showing on national television of the video programme, 'Step by Step', illustrating the programme, gave a great sense of achievement to volunteers and a feeling of pride to parents to see their own children on television.

xi) Meeting with Hindu organisation and VHC to sign contract for the use of the building to accommodate the Unit for disabled children.

1 See Appendix XXI.
2 See Appendix XXXV.

xii) Meeting between VHC, NRC, the researcher and the Chief Education Officer (CEO) to finalise plans for the Unit. CEO approves the release of a teacher to work in the Unit.

xiii) Meetings held between VHC, the researcher and the expatriate womens' group to organise materials to equip the Unit.

xiv) Representatives from VHC meet with local firms to secure donations for the Unit.

5.10 Relationship with IBR facilities?

Before the programme began only six of the children had received help from IBR facilities, none however were receiving help once the programme began. In many cases the parents had been totally isolated, with their disabled child receiving no help from any quarter. Other children simply became too heavy for the mothers to continue taking them to the physiotherapy facilities in the capital. The great majority were therefore unreached by any service.

At the beginning of the programme the relevant health and education facilities were informed about the project and requests were made for appropriate referrals. In practice referrals were only made by professionals with whom the co-ordinator already had a working relationship, however, once the programme was established parents and professionals began making referrals to the programme.

Eleven of the CBR children were referred to IBR facilities, three were accepted into special schools three mornings a week, four received surgical operations or medical treatment and four were integrated into normal schools as a direct result of the intervention of the LS or ILS.

Over time therefore genuine links were established with the specialised services within the country. For some of the parents who benefited from this relationship this was the first time they had realised how they could gain access to such services.

5.11 Cost of the project

Whatever gains may be perceived in the programme, one needs to ask whether in view of the resources expended the progress is meaningful and whether the programme can be financed at a level which could be realistically maintained and introduced into other areas.

The following is a breakdown of the budget for the programme:

1. Income

a) Local:	i) University of Guyana	G$ 8630
	ii) Canadian International Development Agency (CIDA)	5000
		13630
b) Overseas:	i) CIDA	£ 2108.36
	ii) University of London	100.00
		2208.36

2. Percentage breakdown of budget

i) CIDA	80.5%
ii) University of Guyana	16.1%
iii) University of London	3.4%

3. Expenses

a) Local:	i) typing	G$ 1486.90
	ii) paper, ink, stencils	3653.50
	iii) Independent Evaluators	3360.00
	iv) Part-time lecturers	4690.00
	v) misc	439.60
		G$ 13630,00

b) Overseas:	i)	audio-visual materials	£ 845.86
	ii)	psychological tests	359.21
	iii)	books	748.49
	iv)	teaching materials	59.80
	v)	computer software	195.00
			£ 2208.36

Total grants	i)	Local	£ 757.22
	ii)	Overseas	2208.36
			£ 2965.58

The total amount expended on the programme therefore was £2965.58 however a number of points regarding the budget will be considered in the conclusion.

CHAPTER 6 CONCLUSION : NEW DIRECTIONS

6.1 Introduction

The challenge facing rehabilitation in the 1990's can be easily stated; parents are not getting enough help with the care, education and training of their disabled children. In LDCs they often receive no assistance. Responding to the challenge is considerably more difficult. More is known about the inadequacies of the existing service models than innovative alternatives. A simple solution would be to train more personnel, however a widespread expansion of an IBR model of rehabilitation is impractical economically. A radical reappraisal of the concept of staffing, the model of training and the nature of services offered is therefore urgently needed (Mariga and McConkey,1986).

6.2 Is the rehabilitation of the disabled a locally perceived need?

The extensive survey of one rural Guyanese village revealed almost 2% of the child population to be in need of specific help because of their disability. The results of the survey were used by the National Rehabilitation Committee in their advocacy for the establishment of services for disabled children in the rural areas of the country. The Chief Education Officer responded to the survey results by helping the local rehabilitation committee establish a unit for disabled children in one of the villages.

As the CBR programme continued requests came to introduce the project into other areas. Moreover as the programme developed parents and organisations began to seek out the service. Once parents see tangible support being offered to others in their

position they will seek help. The same pattern was evident in Zimbabwe (Mariga,1986), Kenya (Arnold,1986), Indonesia (Johnson and Tjandrakusma,1982) and Pakistan (Rafiq and Jaffar,1986). In this sense CBR became a locally-perceived need. The CBR programme helped to raise the consciousness of parents of disabled children, community organisations and personnel from the Ministry of Education to the need for services within the rural communities.

6.3 Is the concept of simplified rehabilitation a viable response?

The CBR project received enthusiastic endorsement from the Director of the Institute of Adult and Continuing Education who referred to the acceptance by the Institute of the CBR programme as 'one of the best decisions (he) had ever made' [1]. The Ministry of Education also accepted the training programme to be of value to their nursery teachers. The 1987 Annual Report of the National Rehabilitation Committee (NRC) recorded that the CBR programme was 'successful beyond expectation.' In the minutes of the NRC (16 Sept, 1987) the President of the Parents' Association of the Mentally Retarded expressed her Association's wish that the CBR services would expand into other areas of the country. The programme therefore proved acceptable to the key administrators in the area.

Havelock and Huberman (1977) noted the great difficulty of involving key resource persons in innovations in 59% of the cases they studied. In this project the relevant professionals all accepted invitations to participate in the programme as resource persons. Havelock and Huberman (1977:60) recorded the almost unlimited powers of the educational and health establishments to 'obstruct, delay or side track the efforts of

1 See Video, 'Step by Step; a Community-Based Rehabilitation programme in Guyana,' VHS, University of Guyana, 1988.

the innovators.' The rehabilitation professionals lent generous support to the lectures, public meetings, panel presentations, workshops and the graduation exercise and therefore had the feeling of real involvement in the project.There was no objection to the project from any of the rehabilitation therapists in the country, on the contrary, the programme made effective use of the specialised resources available.

Only three mothers declined invitations to become part of the project. One of these mothers subsequently requested help for her child once the child's disability became more obvious. The remainder of the mothers welcomed the presence of the LS. In the final evaluation all the mothers said the programme should be continued. The great majority found the intervention 'very helpful'.Only 1/20 Volunteer Mothers (VM) and 4/18 Nursery Mothers (NM) found the programme unsatisfactory. There were very few comments from the mothers expressing concern about the ability of the LS. The concept of simplified rehabilitation therefore proved acceptable to the administrators, the rehabilitation therapists and the parents.

6.4 Do parents welcome the role of greater involvement in the child's rehabilitation?

The appropriateness of the concept of parental involvement in a Guyanese context was examined in this study through a series of interviews and questionnaires [1]. It was seen that the mothers do appear to share the concept of ages and stages of development. Moreover the mothers believed that children can be helped to acquire certain developmental tasks and gave a number of plausible and logical suggestions concerning how these tasks

1 See p 102-110

could be acquired. The mothers had the belief that they could assist the child's development in the acquisition of basic skills.

Whilst the questionnaire suggested that certain pre-requisite skills necessary to introduce a parent involvement programme clearly existed it also revealed serious practical constraints in performing such a role. 20/39 of the CBR sample were either single-mothers or were grandparents caring for the children. The grandparents often had little understanding of the child's problem and were difficult to get involved in the programme. The fathers' role in the other homes was minimal. The burden of the home was clearly on the mothers' shoulders.

For almost half the parents there was little or no involvement in the project. The parents of the nursery sample in particular tended to deny the child's problem especially as the needs of the slow learner were 'invisible'. In 25% of the homes where both parents were present family life was disrupted by quarrels, fights and frequent separations.

To balance this pessimistic picture 19/26 VM and 15/23 NM claimed they were helped in caring for the child by other family members [1]. Moreover the great majority of the mothers felt the programme did not interfere with their responsibilities and could be successfully integrated into their daily routine [2]. There is obviously no simple prescription for involvement. In a number of cases it was evident that severe practical problems prevented the family from becoming fully involved, some were real material difficulties and others were perhaps barriers of their own making. Some parents who came from similarly disadvantaged backgrounds played major roles within the project. In some of the motivated families the

1 Pre #13,p 286
2 FU #10,11,p 294

mother was able to draw support from an extended family network, in others, single-mothers struggled valiantly to do what they could to assist their children.

The danger of pushing parents further apart by focussing on the mother-child relationship was reviewed in Chapter 2. It should be noted however that the father's role is traditionally limited in society (Mittler, Mittler and McConachie,1985:7), especially in LDCs. Parents may well already have a role division with which they are both content (McConachie,1982:169). The present routine may well have its own momentum which could be threatened by suggesting unrealistic changes. A balance therefore needs to be achieved between encouraging parents to avail themselves of the opportunities provided and feeling pressurised into conforming.

An appreciation of the different ways families lead their lives is necessary; if such considerations are overlooked the danger is that CBR may be no more effective than previous approaches in meeting the families' needs. An essential part of the flexibility is the recognition that parents may not want a role of active involvement in the project. The goal therefore is flexibility in responding to the needs of each family rather than prescriptions of developing services on <u>one</u> model. McConachie (1982:159) offers a reminder that the element of choice should be preserved and the sweeping generalisations of what parents 'need' should be avoided.

At least half of the parents welcomed the role of greater involvement in their child's rehabilitation. For them the goal was not to add one more demand on an already overburdened parent but rather to assist in improving the quality of the interaction between parent and child in the time that was available. Of the mothers who completed the training programme,16/20 VM and 13/18 NM felt they played a key role in

the project. Only 1/20 VM and 3/18 NM felt uninvolved in the programme [1].

A number of variables which could influence the effectiveness of a parent involvement programme were examined. The major variable appeared to be the parents' desire to help the child. Other factors, such as family size, income levels, educational background of the mother and the severity of the child's disability did not appear to be as crucial determinants of the success of the programme as the mothers' attitude towards her child and her involvement in the programme.

6.5 Is the recruitment of volunteers from the community a realistic way of introducing the programme?

Over 60 persons applied to do the CBR programme. There was therefore an element of competition in being 'selected'. The final 30 participants represented a wide variety of experiences, however they all came from humble backgrounds with average family earnings of less than £25 per month. It was not difficult to recruit LSs, for half of them their concern for children and their desire to be of service to the community was sufficient motivation to explain their participation. The majority soon became involved in the course and began to regard the project as their own.

The WHO and Portage-style approaches foster the myth that anyone could be effective as a LS, an illusion which is perpetuated by a high reliance on the hardware of packages and checklists (Dessent,1984:4). The materials however are only as good as the people using them. The qualities needed to be effective in the role of LS need to be examined.

1 Post #4,p 289

The present programme undoubtedly benefited from the presence of volunteers from health and education backgrounds, however no professional training could provide the tact, sincerity and devotion which some of the LSs showed in working with the families. Some of the most effective LSs were housewives with no more than a few years of schooling.

An analysis of the Independent Evaluators' assessments revealed no significant correlation between the LSs' educational background, income and occupation and their effectiveness on the programme. In the nursery sample the key role of a motivated supervisor was evident. In the one school where the Head Teacher was highly supportive of the project, all the staff were involved in the programme, in the other schools where the support was far weaker the attitude of individual teachers was far more variable.

There may never be enough money to train all the professionals that are needed, a re-examination of who constitutes the staff is therefore necessary. the present research suggests that volunteers from the community, if effectively trained and supervised, can play a meaningful role in helping disabled children. More imagination is therefore required concerning the recruitment and deployment of volunteers from the community.

The utilization of resources within the community has potentially far-reaching effects. A number of the LSs reported that the CBR experience had impacted on their lives, increasing their own self-confidence, self respect and feeling of personal significance by realising they could contribute something of value to others. Moreover as Werner (1976:85) notes, if the LS is taught a respectable range of skills, if they are stimulated to think, to take initiative, they can become agents for change, awakening their fellow villagers to their human potential and ultimately, their human rights. The new model of manpower therefore has far reaching implications.

6.6 Does CBR produce meaningful change in children and their families?

The Griffiths Test revealed significant results, at the .01 level on the t test, for both groups of children both at the post-test and, six months later, at the follow-up test. Similar progress was evident on the Portage test. Under control, or baseline conditions, the overall gain was .67 items per month per subtest, under treatment conditions however the figure rose to 1.95. Six months later, at the follow-up, the figure had declined to 1.02 items per month, per subtest. In terms of completed studies there was no noticeable difference in the results between the two groups of children, however where the children are included when the LS stopped working with the family within the first three months of the programme, the results of the volunteer group were consistently better than the nursery teacher sample. Twelve of the nursery teachers did not continue the CBR programme as compared with only two of the volunteers.

Using the criterion established in Tables 5.7 and 5.8 [1] the results when the LS focused on the areas of motor, self-help, cognitive and language were consistently high, in the range of 80-90%. By comparison the rate of success was only 53% when the LS focused on the area of socialisation. It may be the case that the more fundamental skills of movement and language were given higher emphasis by the parents and LSs than socialisation skills.

All of the VM and 12/18 NM noted important changes in their children who were regarded as happier, more mobile, more motivated and better behaved [2], changes which were confirmed by other members of the family [3].

1 See p 132-134
2 Post #3,p 288
3 Post #16,p 290

It should be emphasised that the project was reaching children who, with the exception of six children, had previously received no help whatsoever for their disability. Moreover few of them would be likely to receive any help in the future if CBR was not offered.

When asked to evaluate the programme a number of mothers emphasised the emotional and psychological support they had received from the LSs.The general goals of supporting, caring and befriending the parents identified by Sandow and Clarke (1978) and Dessent (1984) as crucial variables in the Portage programme were also key considerations in the present programme. Cunningham's (1975:185) finding that simply visiting parents regularly and offering genuine positive advice had a significant effect on the way the mother treated the child seemed to be confirmed in this study where parents apparently drew strength from the support offered by the LS. This highlights the limitations of simply focussing on a structured teaching programme and contradicts the advice of Revill and Blunden (1980:22) not to get drawn into a counselling role. The value of the programme may lie as much in the relationship between service agents and family members as in the specifics of the practical intervention which they propose.

All of the VM and half of the NM saw important changes in themselves as a result of the programme, feeling more relaxed, less depressed, happier, more confident and more aware of the child's potential [1]. The changes were however far more characteristic of the VM than the NM [2]. These results from the mothers were confirmed by the LSs who commented on the mother's increased interest and their enhanced knowledge concerning how to help the child [3].

1 Post #3b,p 288
2 Post #21,p 291 SC #1,4,15,p 281-283 Pre #10,p 285
3 LS Int #17,p 315

The concerns of many of the mothers changed from questions about causation to a desire for help in specific areas. They felt more aware of both the child's abilities and his limitations. Their goals became more long term and in many cases, more realistic. Aspirations changed from a desire for the child to be normal to hopes for progress in specific problem areas. Vague goals, 'lead a happy life', became more definite, such as : 'training in feeding'. The changes were characteristic of both groups, however the more significant gains were by the VMs.

The Child Rating Scale recorded noticeable improvements in the Mothers' ratings of their own children following the programme. In the pre-test there was high variability in the attitudes of the VM group, in the post-test however the variability was reduced suggesting the improvements were characteristic of the parents as a whole. The mother's attitude towards the child changed in a number of cases. Before the programme began 23/26 VM spoke of being sad , depressed and worried concerning the child's future [1], only 1/26 VM felt highly confident in dealing with the child [2]. Following the project 15/20 VM had gained that confidence [3], and 9/20 anticipated a bright future[4]. The mothers therefore reported changing over the course of the study in a positive direction. These observations were confirmed by the LSs and IEs in their evaluations.

The programme had a noticeable effect on the mothers attitudes towards the way other family members and the wider community could assist with the child. Initially such thoughts were vague and general [5], however at the end of the programme the ideas were far more specific [6]. Once again, however the gains were

1 SC #1,p 281
2 Pre #9,p 285
3 Post #21,p 291
4 Post #21,p 291
5 Pre #14,p 286 Pre #15,p 286
6 Post #19,20,p 291, SC #12,p 283

more noticeable for the VM. The VM changed their conception of the attitudes held in the community towards persons with disabilities. Initially the mothers regarded the community as generally unsymphathetic and unsupportive [1], by the end of the programme almost half of the VM felt that the community was helpful towards disabled persons [2]. The number of VM who felt free to discuss their child with the neighbour doubled over the course of the project [3]. Moreover the parents were encouraged to seek out contact with other parents of disabled children, 60% found such meetings of great benefit [4].

The great majority of mothers went to some length to explain how valuable the programme had been to them. They appreciated the regularity of the visits, the practical advice given concerning how to stimulate the child, the information on access to IBR services, the care and interest shown by the LS and the fact that someone else valued their child.

Tables 5.12 to 5.17 of the previous chapter illustrate that the only apparent significant relationship between the child's progress and selected variables was the measure of parental involvement [5]. It is not surprising therefore that the more noticeable gains came from the VM sample as this group featured far more parental and community involvement than the nursery group.

6.7 Is community involvement a realistic expectation?

Community involvement is repeatedly exhorted in the literature however it is usually unclear as to what it means. What channel does the community have to express itself? How can the

1 SC #13,p 283
2 SC #13,p 283
3 SC #14,p 283
4 Post #18b,p 291
5 See p 140-141

community feel in control of the programme? How can the community become involved? The co-ordinators of innovations are often high in technical skills but relatively naive in terms of organisational, social and political skills. Promoting community participation is therefore a skill which co-ordinators need to learn. Havelock and Huberman (1977) note that many innovations, which may themselves be effective, have limited long term impact because of the lack of any real involvement of those concerned. The participants and decision makers remain unaware of the potential value of the innovation.

The traditional approach , as Freire (1972) observes, is characterised by one-way directions, the community is never truly involved in the implementation and planning of the programme. Communication becomes an act of making deposits into empty containers, it becomes a dehumanising and patronising experience for the recipients, any gains are only short-lived, the programme rarely becomes self-sustaining. Facilitating community involvement was therefore given high priority in developing the project.

Such participation cannot be brought about by political decree from the top. People will become involved only if they feel genuinely consulted concerning their needs. The goal of development is to influence people, not simply to modify structures. Effective dialogue may be the key, whereby the community learns to solve problems for themselves.

Training needs to focus on the method of facilitating consultation, developing management skills and becoming a sensitive listener. The co-ordinators in the present programme sat with the Village Health Committee (VHC), listened and respected their plans, suggestions were offered but it was always clearly understood who the key actors in the process were . The co-ordinators had a belief in the people. The faith that they could solve their problems with a minimum of outside

assistance was communicated to the villagers. One result of this was that once the formal CBR programme ended the VHC then assumed full responsibility for the programme and helped to establish a Unit for the children of the area.

The theory of participation is that the community should be involved in the planning, implementation, management and evaluation of the programme. The reality is usually that the community passively accept external decisions. The co-ordinators however perceived their role to inspire and advise, not to make unilateral decisions, to assist the LSs and parents in coping more adequately with their own problems.

Behrhost (1975:38) reminds us that we should never create something which cannot be locally self-sustaining. Innovators need to believe that villagers have within themselves most, if not all, the ideas, resources and energy to bring about change. The outsider's role is a facilitative one with temporary infusions of aid or technical assistance, such inputs are however mostly peripheral to the real change process. Great care needs to be exercised to avoid dependency on the LS. The responsibility for the child remains with the parents and is not taken over by the LS. In an effective programme villagers will become more aware of resources which exist in the community and will begin to effectively utilise these services.

One of the encouraging features of the project was the level of community involvement that was generated. The radio and newspaper coverage did much to enhance the prestige of the programme and began the process of community awareness. It was appreciated that an effective innovation requires a well-informed community, time was therefore given to preparing the community in this way. The on-going involvement of the nation's leading rehabilitation therapists and the Parents' Association of disabled children ensured broad-based support for the project and warned away potential critics of the programme.

The financial support of the Canadian International Development Agency and the Universities of London and Guyana gave the LSs an important psychological boost in that they were working on something important. This feeling was enhanced by the presence of the Mayor and leading figures from the University, the Ministry of Education and the Ministry of Health at public meetings co-ordinated by the participants of the programme.

The Village Health Committee which was formed by LSs and parents from the project became an articulate advocate of the needs of the disabled. They played a major role in preparing the community for the survey, mobilising persons from the community to participate in the interviewing and in presenting the results and recommendations to the Ministry of Education. The Committee met with a local Hindu organisation and signed a contract for a one year lease on a building which housed the Unit. The building was offered free of charge by the Hindus and a number of local organisations participated in modifying the hall into a Unit for disabled children. A group of expatriate women played a major role in furnishing the Unit.

Many of the problems of disabled persons are not because of the disability but the attitudes of others around them. A number of attempts were made as part of the research programme to help overcome the feelings of powerlessness, pity and despair that disabled persons evoke in others. These efforts included ; film shows, panel discussions, public meetings, articles in newspapers, radio talks, lectures in schools and the production and showing, twice, on national television of a 30 minute video on the CBR programme. In addition the LSs, on their own, organised two, three-day workshops for parents of disabled children. These events were features of the volunteer programme, the nursery teachers by contrast were not sufficiently involved to generate such community participation.

Whilst one needs to be sensitive to local attitudes it is all too easy to postpone action with the noble rationalisation that the community is' not yet ready.' A balance needs to be achieved between moving too fast and too slowly, between being responsive to locally perceived needs and to providing leadership and initiative. The present rural outreach programme and the plans to establish a resource unit for disabled children of the area would not have been done by the community without the outside catalyst that was provided. The new role of the rehabilitation therapist in the area of community development is to help the community examine their own problems and help them realise they have, within themselves, the capacity to meet those needs. The significant role played by the Village Health Committee in the present programme suggests that community involvement in the area of rehabilitation is a feasible proposition.

6.8 Does CBR establish effective links with IBR?

WHO have done little to establish a working relationship between these two branches of rehabilitation when they reject the efforts of IBR services as being 'obsolete and useless' (Helander,1984:133).

Before the programme began only six of the children had been exposed to specialised help for disabled children [1], the remainder had received no professional help beyond routine medical examinations at the local clinic. However because of transportation problems none of the children were attending IBR facilities when the project began. By the end of the project eleven children had been referred to IBR centres and all the families were highly satisfied by the results [2]. Four of

1 Pre #6,p 285
2 Post #13,p 290

these children were accepted in the regular school as a result of the intervention of the LS and the ILS. However they simply languished at the back of the class and were tolerated as long as they did not make demands on the teacher or disrupt the class. Their integration may have done something to increase community awareness and promote a measure of social rehabilitation but it did precious little for the specific needs of the child. On the other hand three children gained places at the specialised centres in the capital but attended sporadically and soon found the burden of daily travel too demanding . Even the specific referral for orthopaedic shoes was rendered ineffective because of the lack of understanding as to how the boots should be used [1].

The process of referral was effective in the cases where operations were needed. In D's case [2] the LS was successful in introducing the mother to the necessary surgical help that could greatly help her child. In this case the LS helped to make IBR services comprehensible and accessible to the mother.

The programme was therefore effective in introducing a number of children to more specialised facilities available in the capital, however the access to the special centres proved temporary and the integration into the regular school appeared to be fragile. An intervening stage between IBR and CBR may therefore be necessary to span the gap between these two approaches. This will be discussed in a later section.

1 See p,164
2 See p,165-166

6.9 Is CBR cost effective?

Whatever gains may be perceived in the programme, one needs to ask whether in view of the resources expended the progress is meaningful and whether the programme can be financed at a level which could be realistically maintained and introduced into other areas.

Cost-effective data on CBR projects is rarely reported in the literature, when it is the figures per child; Jamaica US$150 (McIntosh,1980), Kenya US$150 (Arnold,1984) and Malaysia US$490 (Jaekle,1986), are far in excess of the modest US$9 quoted by WHO (Mendis and Nelson,1983:12; Helander,1984:135).

The total sum received for the present study was £2965.58 [1]. When considering the budget two points need to be considered. Firstly, because of a series of problems on the part of the suppliers a good deal of the materials did not arrive until the project was near completion. This forced the participants to be more creative and resourceful in utilising what was readily available. Secondly much of the material is available for use with another project. This includes: audio-visual equipment, psychological tests, books and computer software. A more accurate estimate for the cost is therefore:

	total grant	£ 2965.58
-	materials available	1629.50
		1336.08

1 The official exchange rate, at the time of the project, was £1 = G$18. The expenses of the project are given in Appendix XXXVIII. The list of materials which could be used in another project are given in Appendix XXXVIII.

The cost per child, per year is £1336.08, divided by 39, (the number of children who completed the training programme). This figure is then divided by 1.25 (ie the duration of the project in years). The cost per child, per year is therefore £27. The project was therefore financed at a considerably lower level than the other CBR figures quoted earlier .

Whilst the present figure is significantly lower than other figures it is still no economic miracle. The figure includes payment for the co-ordinators' time , however it does not include any estimate of the costs of using IBR facilities in the form of special educational provision or surgical intervention. Whatever the precise figure, change will only come about when some level of investment is made in the area. Presently there is no budget for rural rehabilitation. Moreover the very provision of services, however rudimentary, awakens unmet and unrecognised needs. The true financial implications for an effective CBR programme may therefore be considerable.

6.10 How was the WHO scheme modified and why?

i) Introduction: Much of the literature evaluating innovation in the areas of health, education and rehabilitation in LDCs is pessimistic in tone (Adams and Chen,1981; Havelock and Huberman,1977). In spite of large scale investments, few projects have been effective and most remain as giant pilot projects characterised by poor planning, grandiose objectives, bureaucratic entanglements and a fundamental lack of appreciation of the process of innovation itself. A major reason for the lack of effectiveness may lie less with the nature of the innovation package than the method of introduction. Attempts were made to overcome some of these problems in this project.

ii) Model of innovation: The WHO method of introducing CBR is based on a Rational-Empirical model (Whiteside,1978). Parents are regarded as waiting and eager for new ideas, they only need to be properly 'informed' and they will change their behaviour. there is an underlying assumption that parents will be receptive to innovation. The WHO approach is characterised by a one-way channel of communication with a high reliance on the printed word as the medium for change. It is based on a model of research, development and diffusion with the recipients only playing a passive role in the process. Such approaches are generally regarded as being managed and executed by outside, not local, agencies, thereby extinguishing local support and initiative.

By contrast a Normative-Educational model of innovation (Whiteside,1978), such as the one adopted in the present study, recognises the limitations of relying on rational persuasion or administrative legislation. The goal is to influence people, their perceptions, attitudes and behaviours. The focus therefore needs to be on persons as the point of entry rather than on goals and structures of the organisation. It is people who design, accept and implement changes.

iii) Good foundation established before beginning project: The co-ordinators of the project had a good understanding of local conditions. One was a highly respected Guyanese physiotherapist who has worked as a Consultant for WHO in the area of CBR. As a prominent figure in the Ministry of Health she proved a very valuable'shield' from any potential criticism from within the medical personnel.The other co-ordinator, the researcher, had worked for ten years in Guyana and had fairly wide contacts in the area of education. The researcher had earlier introduced a programme for the training of teachers in the area of special education and had learnt something of the challenges of introducing innovations. It was understood that

without administrative support the project would encounter resistance and would ultimately fail. Careful attention was therefore placed on a sensitive preparation of the host culture, something that was overlooked in many of the innovations reviewed by Havelock and Huberman (1977:8).

WHO suggests using the Primary Health Care (PHC) system as the means to introduce CBR, however this system is not well developed in the Coastal region of Guyana. Moreover the researcher's contacts and expertise lay in the educational field, it was therefore decided to work through teachers from the Ministry of Education and volunteers from the Institute of Adult Education. The Institute programme provided considerable flexibility and the Ministry approach offered a potential way of maintaining the goals of the programme if the project proved successful.

Although the project was adequately funded a series of administrative problems on the part of the major suppliers meant the late arrival of much of the materials, however, in anticipation of such delays, essential teaching materials were laboriously typed.

The involvement of local opinion leaders such as the Parent-Teachers' Association of the school where the training was based,the Parents' Association of Mentally Retarded Children and the Village Health Committee, combined with articles and announcements in the local media helped to give the participants the feeling they were working on a real, urgent problem. The involvement of the key rehabilitation professionals at the planning stage helped offset some of the potential criticisms of the innovation as the project was perceived as a joint venture rather than the idea of one person.

The project was introduced as an experiment, not as a panacea. It was not presented as revolutionary or controversial but as questioning the potential of the approach. Such caution was ignored by WHO when, in promoting CBR, they caricatured the IBR approach and made dramatic claims for the merits of the new service (Serpell,1986). Such a caricature only arouses opposition to change from the ruling elite (Havelock and Huberman,1977).

The programme was deliberately planned on a small scale despite the invitations from a number of sources to increase the coverage into other regions. The small scale however allowed quick and efficient communication, co-ordination and decision making. The programme was regarded as a demonstration project to see what could be achieved with relatively modest investments, however, at the same time, thought was given to see how the gains of the programme could be maintained.

The idea for the programme came from the researcher , however the concept was soon shared and became a joint enterprise on the part of a number of persons in the education and health fields. The programme was deliberately planned to have a number of principal participants. Both co-ordinators played key roles in mobilising the resources existing within the country. Shrewd judgement was also necessary to identify potential vocal critics of the programme and get them involved in the programme at the outset so that they would regard the innovation as part of their own work too. It was appreciated that to have a lasting impact the innovation needed good relations with government at the highest levels, to achieve this the programme had to work within government structures and not seek to create new ones.

A strong foundation for the programme was therefore established at the outset, based on: clear commitment by the co-ordinators, keen interest of the LSs, adequate financial support both locally and overseas, administrative support within the Ministry of Education and the assistance of rehabilitation professionals and Parent Associations. No important ingredient was regarded as missing at the outset.

In contrast to the WHO pilot-projects which were conducted under favourable conditions , the Guyana programme was carried out under fairly severe socio-economic constraints within the country. Mid-way through the project a devaluation effectively reduced everyone's salary by 127% (Stabroek News,Jam 30th 1988, p9). Throughout the project the evening sessions were plagued by blackouts. Transportation was an ever-present problem and there were two periods of serious petrol shortages to contend with. These difficulties took a greater toll on the nursery teachers than the volunteers and contributed to a group of people living on a very modest income.

iv) <u>High emphasis on on-going training</u>: WHO do not appear to give high priority to training and supervision when they suggest:

> refresher courses can be held whenever necessary, perhaps once a year...arrange for LSs...to meet together at least once in every 3 months (Mendis and Nelson, 1983:71,73).

By comparison, following several weeks of intensive training, a series of regular refresher workshops were organised in some of the effective, non-WHO, CBR programmes reviewed earlier (Jaekle,1986; Berman and Sisler,1984; Jesien,Aliaga and Llanos,1979; Arnold,1986). The effective programmes included extensive and prolonged follow-up activities, reflecting the way in which these projects do not underestimate the magnitude of the task they face. Throughout the Guyana programme on-going workshops were held for the LSs.

v) Changed role for rehabilitation therapists: The key to improved services depends on a more innovative approach to manpower utilization and preparation (Mittler,1983:47). The challenge for the therapist becomes learning how to give away their skills, that however may prove to be one of the most demanding tasks for professionals to learn (McConkey, 1986:27).

The new role for the therapist is to nurture the abilities within the child, home and community and to facilitate and support the family and the volunteer. Training needs to focus on the rationale for this co-operation and help overcome the unrealistic expectations parents and therapists often have for each other.

The role of the therapist is to inspire and advise, not to make unilateral decisions. The goal is to show villagers how they can cope more adequately with their own problems. This faith of the planners in the abilities of village people is largely missing from the WHO analysis. The Guyana project established a Unit for disabled children in one of the rural areas. The Unit became the responsibility of a committee from the community. One challenge was to help overcome the pervasive feeling in rural LDC communities that only some external force can solve their problems. A major goal for the therapist is therefore as promoter of community development.

vi) New model of supervision: The WHO concept of supervision is conceived in a mechanistic fashion. An attempt was made to adopt a more supportive model of supervision in this study. Various professionals visited the children in their homes along with the LS. The therapists' role was supportive, giving suggestions and comments as necessary. One of the major goals in the supervision was to promote confidence in the LS and to develop the respect of the family for the LS. The therapists remained in the background and did not attempt to take over

responsibility for the child from the LS and the family. This model could only be implemented if a sincere and close relationship had developed between the co-ordinators and the LS. Such a relationship depends on effective human relations and cannot be programmed into existence.

vii) Flexible curriculum: The WHO training model (Mendis and Nelson,1983), though valuable was regarded as too rigid. An attempt was made to achieve a balance between the careful advance planning advocated by WHO and maintaining a flexible, open-ended approach. WHO offer a series of clearly identified tasks which constitute the learning objectives of the curriculm. It tends to become a'closed-systems' approach, relying on predictability of outcome. However the exact role of the LS cannot be totally predictable if they are to be effective. An attempt was therefore made to adopt an approach which emphasised process not content.

Every ten weeks the LSs met with the ILSs to discuss the programme to date. They began to feel the programme was their own, they became active planners rather than passive recipients. Their ideas were listened to, respected and adopted. Some of the most creative ideas for the project came out of these sessions. The LSs were challenged to be imaginative and were not merely asked to follow a script. A crucial role of the ILS was to facilitate this process and not simply direct their every step.

In none of the effective programmes reviewed was the LS simply following a rigid, prescriptive manual. Indeed in a number of cases the value of a written manual in a LDC context has been questioned (Miles,1985b; Ogunkoya,1982; Thorburn,1983). However the WHO Manual has served the important function of stimulating the local production of teaching materials suited to the demands of their own particular culture. This has been achieved

in Jamaica (Thorburn,1983), Viet Nam (Mendis,1988) and the Phillipines (Periquet, 1984). As a global reference work Werner's 'Disabled Village Children' is far more detailed, better organised, clearer and more visually appealing than the WHO Manual.

A creative and innovative curriculum has been adopted in Zimbabwe with extensive use of locally produced materials (Mariga and McConkey,1986). A set of illustrated cards has been designed with a graded series of simple activities for the child, a series of video programmes, shot on location, have been produced to illustrate the key activities on the cards. The LSs are therefore given tangible tools for translating knowledge into practice. All the resources are tailored to the cultural, linguistic and literary needs of the clients. McConkey (1986) has clearly demonstrated the value of video in transforming the way we share information with others.

The present programme adopted the WHO curriculum as a base and then added elements from the Portage materials, Hester Adrian Research Centre ideas and aspects from the Zimbabwe programme.

viii) Parent Associations: The establishment of an effective partnership is missing from the WHO analysis. Many social and emotional needs of parents can more effectively be offered by participation in an informal voluntary association with other parents of handicapped children. The script for the partnership evolves from the parents themselves. Parents want to meet other parents (Thorburn,1983; Arnold,1984; Serpell,1986; Kohli,1986). It is agreed in theory, however there is little information on actual practice.

Few of the parents in the Guyana programme had met other parents of disabled children before the project began. However 18 months later the majority had met other parents and found

the meeting very helpful in realising they were not alone with the problem [1]. Bannister (1985:107) argues that negative feelings about the child can best be overcome in a supportive relationship with another parent who is able to construe more accurately what will reassure a parent. CBR should be supplemented by the establishment of a local network of families who could provide mutual support to one another. Such a network could provide a formidable force in working for change in LDCs.

ix) Co-ordinator's role: The WHO underplay the key role which needs to be played by the co-ordinator. This is clearly apparent in the effective programmes in Zimbabwe (Mariga and McConkey,1986), Kenya (Arnold,1986) and Malaysia (Jaekle,1986) where visits, lasting several days, are made to outlying areas by ILSs highly committed to the project. Jaekle (1986) stresses the key part the co-ordinator played in inspiring commitment and dedication in the LSs. When asked to evaluate the present programme a number of LSs mentioned the important function played by the co-ordinators in supporting and encouraging their efforts.

The co-ordinator's major task is not that of a lecturer, administrator or legislator but a facilitator of human relations. The goal is to help persons identify their own problems and assist in formulating creative responses to the problems. A crucial consideration in this approach is to know when to stand back and allow clients to take the programme in the direction they choose. In the present project the Village Health Committee, in collaboration with the National Rehabilitation Committee, assumed responsibility for the programme by liasing with the Ministry of Education concerning

1 Post #18,p 291

the creation of a Unit for the disabled children of the area. At this stage the co-ordinators needed the humility and the wisdom to stand back and allow these groups to take charge. In doing so the programme developed into a community project and not a programme piloted by an outside force.

A typical problem in innovations of this nature is disunity among programme staff especially where expatriate and local staff work together (Havelock and Huberman,1977:97). This project was a joint venture with the researcher working alongside a counterpart who was internationally recognised as an expert in the area of rehabilitation, it was never the case of an expatriate 'imparting knowledge' to a local professional.

6.11 Limitations of CBR model

i) Is CBR a realistic way of closing the gap between need and available provision? The real test for CBR is yet to come, can CBR expand beyond a relatively small-scale home-based teaching model into a nation-wide, community care programme?It remains to be seen how many persons could be helped with the CBR approach. The present project revealed that it was impractical for the LSs, whether volunteers or nursery teachers, to work with more than one or two children. In a follow-up study it is hoped to work with a core of full-time workers to see if such a model can begin to make an impact on the magnitude of the challenge.

ii) For whom is CBR a relevant approach? : For some of the parents in the present study, poverty, overcrowding and ingrained negative attitudes made involvement in the programme impractical. In a number of cases there was simply no one available in the home through which to introduce the programme, other parents sought comfort in Black Magic, on the other hand

there were parents from equally disadvantaged backgrounds who were able to rise above their circumstances and play major roles in the project. Cathy visited her paralysed husband in hospital daily and yet found time, through the tact, wisdom and patience of the LS, to stimulate her cerebral palsied child to make progress in moving. Mavis, with a severely physically handicapped son of seventeen years of age, had given up her job to care for her son and would carry him to evening sessions to learn how she could be more effective. In Nalini's home there was no furniture, the family were obviously very poor, nevertheless sacrifices were made to ensure her son could take advantage of surgical operations that were made available. Cunningham and Davies (1986;68) offer a reminder that families with disabled children were just ordinary families before the arrival of their child. The great range of parental responses as seen in this programme should not therefore be surprising.

The sample was very small to allow suggestions as to which children might be more likely to profit from the approach. Six of the eight physically handicapped children showed marked or moderate improvement. As a group they benefitted from referral to specialist facilities. The mentally handicapped children were more evenly divided between the various categories of progress suggesting that the nature of the child's handicap may impose limits on what is possible. Whilst those limits should be constantly tested, one needs to present a realistic picture to parents concerning the possibilities (McConkey, 1986:107). The present study suggests that some children, noticeably those with severe hearing impairments, may need more specialised services than those offered by the CBR approach.

The philosophy underlying parental involvement is not alien to a Guyanese culture, however, real, practical constraints need to be appreciated. Some parents may enthusiastically embrace the teaching role, for others the role is too demanding. More research is needed concerning the precise variables within the

child, family and community which contribute to effective programmes. The one certain conclusion is that no easy stereotypes prevail concerning for whom CBR is relevant.

iii) Through what infrastructure can CBR be introduced?: WHO have advocated Primary Health Care as the infrastructure through which to introduce CBR. In some cases that may be realistic. In Mexico the Community Health Workers were young women from the community who had earned the respect and confidence of the villagers (Hindley-Smith, 1981). In Northern Kenya the only mechanism through which to establish rehabilitation was the health system (Arnold, 1984). The Village Health Workers were already working closely with the families in their homes and were the key moulders of attitudes in rural areas. In these cases the manpower existed and simply needed additional training and orientation rather than major capital outlays.

In the Guyana project attempting to work through the nursery school system proved to be a demanding exercise with only a minority of the teachers becoming fully involved in the programme [1]. As a group the teachers were preoccupied with their own concerns, almost half of the group could think of no better reason for participating in the project than 'wanting more information on the disabled.'

There may well be a significant difference between attempting to 'add on' rehabilitation tasks to professional roles which are already established and incorporating the responsibilities into job specifications from the inception. In Guyana for example an effective CBR module has successfully been included

1 6/25 teachers were 'highly involved', 14/25 showed either 'passive indifference' or did not participate at all. see p127

in the training of Physiotherapist Assistants (Maison-Halls, 1988). It is significantly more demanding to incorporate the responsibility into professional roles that have been clearly defined for many years.

Whilst there is undoubtedly a key role that volunteers can play in this area, inspired leadership and the enthusiasm of volunteers are not enough. The volunteers are effective in providing a form of social, psychological support, however they are obviously not equipped to handle the more specialised needs of the children.

Imaginative and creative investigation of the available resources in the community is a vital first step in the planning of the services. It should be remembered that CBR is not 'a' service, as McConkey, (1986) notes, it is a philosophy of care which inevitably embraces many forms of services.

Investigating creative ways of expanding the contribution to be made by volunteers and incorporating CBR into the remit of workers already involved in service projects are crucial to closing the gap between the need and the available provision. The present research suggests CBR can play a significant contribution, politicians, administrators and professionals now need to consider the infrastructure and training needs which are necessary to fulfil the potential.

iv) Can the battle between CBR and IBR be resolved?: IBR was invented by WHO to identify something that they felt needed to be changed, however it became a caricature (Serpell, 1986). CBR and IBR can be more usefully regarded as complementary, the strengths of one counteracting the weakness of the other. IBR is often dismissed for utilizing a disproportionate share of the resources for only a privileged few. The very real

strengths of the IBR facilities are overlooked in the emotional debate. Professionals possess specialist knowledge and confidence in their abilities which is infectious. Institutions nurture an accumulation of experience, provide opportunities for in-service training, the possibility of breakthroughs and much valued relief of family burdens.

There is also a potential danger of CBR providing only superficial services because of limited training, allowing mistakes in the application of poorly understood techniques to go uncorrected for long periods (Serpell, 1985). Moreover the logistics of attempting to use the limited rehabilitation therapists as supervisors of widely scattered client population is often overlooked.

A programme based on volunteers should do a great deal to increase community awareness and to help get the community and family members sensitised to the needs of children for respect and integration into both family and community activities. However volunteers alone may be able to do very little in terms of the more technical aspects of rehabilitation (Werner, 1988).

The antithesis of IBR and CBR is artificial, in moving away from IBR the pendulum has swung too far in the opposite direction. CBR no doubt has great potential, however without adequate rehabilitation therapists to supervise the work, CBR will be no more successful than PHC has been ir comparable circumstances.

Miles (1985b) has clearly demonstrated the value of intermediate community- based rehabilitation centres with mid-level trained rehabilitation workers, run by the community, using local materials and offering a valuable training base for parents and professionals from other areas. Such a centre is perhaps essential to make the link between the volunteers and the professional services. Also, as Werner (1988) notes, the

sustainability and the technical quality of the programme will in large part depend on this intermediate link.

The children in the present programme have the choice of either staying at home or being 'accepted' at the regular school only to occupy the 'back seat'. It is to be hoped that the creation of the Unit in Grove may be a step towards establishing an intermediate link between the volunteers and therapists.

Mittler (1984) warns against the danger of drawing simplistic conclusions. Britain has approximately 500 special schools. Teachers are constantly updating their knowledge and skills and introducing innovations in content and method. Such a valuable resource cannot be dismantled. In LDCs the services are obviously not so developed. It is perhaps there where a new pattern of services can be most easily established. Unfortunately CBR and IBR have been regarded as mutually exclusive when in reality they are potentially complementary. The debate has become emotional and views polarised. Therapists and planners in LDCs have the challenge of reconciling the debate.

6.12 Suggestions for further study

WHO has provided a key leadership role in suggesting a new model of service to meet the pressing needs. It is however left to practitioners to see how the original WHO scheme needs to be supplemented. The present research suggests some avenues which need to be explored further.

i) Movement from a pilot project to widespread implementation: Innovations, by nature, are artifacts creating changes which would not normally occur and which are artificially kept alive by special energies, funds and expertise. The challenge is to see what happens when the protected subculture disappears and the temporary system is absorbed into the government system, using local officials not so committed to the project.

The present project demanded considerable involvement from the researcher. Part of the expansion therefore will be to pilot the programme in situations more comparable to normal conditions. Attempts will be made to integrate the CBR services into the remit of agencies who are already working in these regions.

A proposal has been submitted by the researcher to the European Economic Commission (EEC) to introduce CBR in three coastal regions and two interior areas of Guyana. The objective is not simply to replicate the model developed here but to investigate creative ways of helping the communities develop their own CBR programmes. A significant part of the EEC proposal is the development of video-materials which could be used to help train others to run such programmes and to develop more culturally appropriate training materials.

Attempts will also be made to investigate the skills necessary on the part of the co-ordinator to manage such a project. Cunningham and Jeffree (1975) observe that such training is no easy task. They tried to substitute teachers for psychologists as facilitators of parent workshops and found the attendance of the parents at the sessions to drop off significantly. The teachers were simply not equipped to handle the demands of the role. Moreover, Cunningham, Anmonier and Sloper (1982) illustrate how demanding the role of the facilitator is when 70% of their sample of qualified Health Visitors expressed their feelings of inadequacy concerning visiting the homes of

handicapped children. In our enthusiasm to embrace the philosophy of home-based care we may fail to appreciate the very real demands such an approach makes on the key players.

ii) Frequency of visits: There is persuasive evidence that suggests greater progress when LSs visit less regularly than every week (Buckley, 1984; Sandow and Clarke, 1978; Sandow et al, 1981). The parents who were visited less regularly retained the role of protagonists, were less dependent on the home visitor and invested more effort in helping the child. Attempts need to be made to see if this research evidence would be relevant in a LDC context.

iii) What is the key contribution the LS makes?: Influencing parents' attitudes and expectations and nurturing the belief that the child is capable of learning and worth helping may be the crucial contribution the LS can play. A sensitive analysis of the role the LS plays in the home would have important implications concerning the focus of the project. If attitudinal changes prove to be the key variable this would significantly influence the type of training programme offered the LS.

iv) Examination of interactions: The proposed catalyst of change is the relationship between the LS and the mother and between the mother and the child. A more detailed study of these relationships is necessary. The intervention clearly has different kinds of impact on various families. There is a need to examine the characteristics of the family and their environment that facilitate the development process and investigate which dimensions of the interaction are more open to change.

v) Parent Associations: Greater work needs to be done to see how the development of Parent Associations can be encouraged and to see how they could develop an advocacy role.

vi) Partnership: A code of ethics needs to be developed to help LSs understand when they may be dealing with a client who needs more specialised help.

vii) Professionalisation: With the emergence of professional training courses in CBR one needs to consider whether there is a danger in professionalising the essential spirit that makes CBR so effective in its best examples. The present research suggests that the befriending, caring role was an essential ingredient in the effectiveness of the interaction of the LSs with the family. One needs to ensure that in securing a formal qualification in CBR one does not lose touch with these interpersonal skills.

6.13 Conclusion

Follow-up data would be necessary to see how well the parents have been trained and how motivated the community is to maintain the gains on their own. It may be too early to say how permanent the changes in behaviour are, however the project has demonstrated what can be achieved, at low cost, to create not only better opportunities for the child, but a sense of hope on the part of parents that they can play a significant role in the development process. The community has become more aware of disabled persons in their midst and played a major role in planning ways of meeting their needs. For those who required more specialised help IBR services became more relevant and

accessible. In the final analysis, it is people that make a programme work , the CBR programme was effective in mobilising and inspiring a group of volunteers to take on the challenge of working with disabled children.

The project presented a new approach to rehabilitation to policy makers, planners and community leaders in the country. The programme trained a dedicated and competent cadre of LSs who may continue their work formally and informally with other children.

All the children gained something, some gained more than others. Some effectively made use of what was offered, others may soon forget. If the goal is to serve, many of the families were served well and the project was a success.

Progress has been slow and uneven in this area, it is however significant that some of the more creative examples of parent-professional co-operation have come from the third world. The Zimcare project in Zimbabwe has been developed by one full-time worker with the support of one part-time assistant and yet the service helps in excess of 300 people (McConkey and Mariga, 1986). It may be a case of the West looking to the 'new world' for innovative ideas of meeting the challenge of working with children with disabilities.

As the Decade for the Disabled draws to a close it becomes evident that the challenge has yet to be met. Traditional methods can do no more than scratch the surface. A radical reappraisal of the role of the rehabilitation therapists as promoters of community development is necessary, and CBR offers such a role. If we lack the vision and courage to tread new paths, the danger is that more reports will be written, more slogans devised, more rhetoric uttered and still 98% of the disabled population will remain totally unaware of the international concern being voiced on their behalf.

APPENDICES

Appendix I

Items deleted from the Portage Checklist

The following items from the original Portage Checklist were deleted for the purpose of the research study:

L 88: 'Tells telephone number'

SH 64: 'Puts on mittens'

SH 97: 'Adjusts water temperature for shower or bath'

SH 101: 'Finds correct bathroom in public place'

SH 105: 'Buckles own seat belt in car'

Child Development Questionnaire

Name of Interviewer:
Date:
Name of subject:
Ethnic group: African/Indian/Chinese/Portugese/European/
Amerindian/Mixed

1) **Household Data:**
   i) Household Composition: Mother and Father/
   Mother alone/
   Father alone/

2) **Roles within the family:**
   i) Who looks after the child during the day?...
   ii) Who looks after children in the evening?...
   iii) Who dresses the children?...
   iv) Who changes the young children?...
   v) Who feeds the children?...
   vi) Who washes the young children?...
   vii) Who puts the children to bed?...
   viii) Who does the shopping?...
   ix) Who does the washing up?...
   x) Who cooks?...
   xi) Who cleans the house?...

3) **Knowledge of child development:**

At what age do children:
   i) walk unaided?...
   ii) dress unaided?...
   iii) feed unaided?...
   iv) wash unaided?...
   v) become dry by day?...
   vi) say words?...
   vii) sit on floor without support?...

Can a child be helped to learn to walk? Yes/No
   i) If No: why not...
   ii) If Yes: how would you do it...

Can a child be helped to feed unaided? Yes/No
   i) If No: why not...
   ii) If Yes: how would you do it...

Can a child be helped to become dry by day? Yes/No
   i) If No: why not..
   ii) If Yes: how would you do it...

Can a child be helped to say words? Yes/No

i) If No: why not...

ii) If Yes: how would you do it...

4) Child rearing practices

i) When you are with the children what do you do?...

ii) Do you give the children anything to do?...

iii) Is there anything the children particularly enjoy?

iv) Do the children have any toys?...

v) Do you play with the children?...

vi) If yes: what do you play?...

Child Development Questionnaire: background information

Table 1: Ethnic background of subjects

African	75	55%
East Indian	32	23%
Mixed	17	12%
Amerindian	5	4%
Chinese	3	2%
Portugese	4	3%
European	1	1%

Table 2: Demographic backgrounds of subjects

Urban	86	63%
Rural	51	37%

Table 3: Household composition

Mother alone	33	24%
Father alone	2	2%
Mother & Father	100	73%
No response	1	1%

Table 4: Number of children in the family

1	20	15%
2	44	32%
3	22	16%
4	21	15%
5	10	7%
6	7	5%
7	5	4%
8	5	4%
9	3	2%

Table 5: Roles within the family

"Who looks after the following tasks in the home..."

	Mother		Father		Mother/ Father		Relative		Other	
Looks after child during day	66	48%	2	1%			23	17%	46	34%
Looks after child at night	83	61%	1	1%	34	25%	16	12%	3	2%
Dresses the child	70	51%			26	19%	32	23%	9	6%
Cleans young children	71	52%			22	16%	28	20%	16	12%
Feeds children	53	39%			33	24%	39	28%	12	9%
Baths children	66	48%			24	18%	21	15%	26	19%
Puts children to bed	64	47%	4	3%	30	22%	14	10%	25	18%
Shopping	78	57%	5	4%	38	28%	11	8%	5	4%
Washing	68	50%			31	23%	28	20%	10	7%
Cooking	83	61%			27	20%	20	15%	7	5%
Cleaning	69	50%	2	1%	29	21%	28	20%	9	6%

Table 6: Role of teaching in achieving developmental tasks

i) Can a child be helped to learn to walk?		
Yes	113	82%
No	21	15%
Uncertain	3	2%
a) Explanation for a positive answer:		
use walker	26	19%
physical support	64	47%
verbal encouragement	6	4%
other reasons	12	9%
no reason	5	4%
b) Explanation for a negative answer:		
comes naturally	14	10%
dangerous	1	1%
no reason	6	4%
ii) Can a child be helped to feed unaided?		
Yes	120	86%
No	13	9%
Uncertain	4	3%
a) Explanation for a positive answer:		
demonstration	21	15%
physical support	19	14%
feeding cup	5	4%
guiding hand	15	11%
verbal encouragement	3	2%
trial & error	9	7%
other reasons	28	20%
no reason	20	15%
b) Explanation for a negative answer:		
maturation only	4	3%
dangerous	3	2%
no reason	4	3%
other reason	2	1%
iii) Can a child be helped to become dry by day?		
Yes	109	80%
No	12	8%
Uncertain	16	12%
a) Explanation for a positive answer:		
use potty	74	54%
verbal encouragement	4	3%
use towel*	8	6%
other reason	10	7%
no reason	13	9%
b) Explanation for a negative answer:		
maturation only	6	4%
no reason	6	4%

* these respondents misunderstood the question

iv) Can a child be helped to learn to say words?

Yes	131	96%
No	3	2%
Uncertain	3	2%

a) Explanation for a positive answer:

imitation	107	78%
label objects	13	9%
examine mouth & lips	4	3%
verbal encouragement	6	4%
no reason	1	1%

b) Eplanation for a negative answer:

maturation	2	1%
no reason	1	1%

Table 7 Child rearing practices

i) When you are with the children what do you do?

play	40	29%
talk to them	45	33%
tell story	18	13%
sing	5	4%
nothing mentioned	10	7%
anything necessary	5	4%
school work	1	1%
other things	11	8%

ii) Is there anything the children particularly enjoy doing?

TV/cinema	15	11%
walking	6	4%
housework	22	16%
play with toys	6	4%

Appendix IV

Portage Checklist Behavioural Objectives

A) **Language**

1 Child (Ch) imitates 'ah' sound on request on 4/5 trials.
3 Ch imitates clapping hands when shown on 4/5 trials.
4 Ch responds correctly to the statement 'give me your hand', when accompanied by an appropriate gesture , on 4/5 trials.
6 Ch either nods or shakes head when asked 'do you want a drink' on 4/5 trials.
8 Ch imitates a shout and a whisper when demonstrated on 4/5 trials.
10 Ch vocalises in response to speech of another person 90% of the time.
12 Ch uses the word 'more' when he wants something extra 75% of the time.
13 Given a verbal model, ch repeats 'all gone' in appropriate situations 75% of the time.
14 Ch carrys out the following directions, given without gestures, 'sit down, stand up, come here',on 4/5 trials.
15 A cup, spoon and ball are presented to the child in an array of 3 , ch indicates the appropriate one when requested 90% of the time.
17* Ch presented with pictures of: tree, ball, cup, pencil and banana in an array of 5. Ch points to 4/5 objects when named.
18 Ch points to:eye, nose, mouth when requested verbally on 4/5 trials.
19 Ch gives his own name when asked 80% of the time.
20 Ch presented with the objects: block, car, ball, in an array of 3 . Ch gives the correct name for the object 80% of the time.
24 Ch produces an appropriate sound when requested for a cow and a dog 80% of the time.
25 Ch presented with: milk, biscuits, rice in an array of 3. Ch gives correct name for object 80%of the time.
26 Ch uses a rising intonation at the end of questions 80% of the time.
27 Ch names: eye, nose, mouth when indicated on another person 80% of the time.
28 Ch answers questions: 'are you hungry/tired' with a yes/no reply 80% of the time.
31 Ch uses an appropriate word to indicate toilet need 90% of the time.
35 When observing someone washing, ch says what they are doing when asked on 4/5 trials.
36 A ball is placed on the floor. Ch says where the ball is when requested on 4/5 trials.
37 Ch identifies the sounds of a car driving and a dog barking 90% of the time.

38 Ch given 3 blocks and asked what they are.Ch uses plural form of blocks 90% of the time.

40* Ch presented with pictures: comb, chair, cup, hat, pencil, bed, spoon, shoe, bicycle, ball, in any array of 4. Ch points to the appropriate picture when described by its use 90% of the time.

43 Ch carrys out the command 'put the ball on the floor, kick the ball,' 90% of the time.

44* Ch shown pictures of children running, eating, and fighting and asked 'what are they doing'. Ch uses -ing verb form 90% of the time.

45 Ch uses the regular form 80% of the time.

51 When asked 'whose slipper is this?' ch says 'mine' rather than giving his name, 90% of the time.

52* Ch presented with pictures: shoe, ball, cup, in an array of 3 can point to which is not a ball, 90% of the time.

53 When asked the question,'who is this' (pointing to the mother) ch responds 'Mummy' 90% of the time.

56* Ch presented with 3 pictures of animals and asked what name could be given to all of them.Correct on 4/5 trials.

60 Ch attends for 5 minutes while story is being read on 4/5 trials.

62 Ch gives full name when requested 80% of the time.

66 Ch explains what scissors and a hammer are used for on 4/5 trials.

69* Ch says the word 'children' when shown a picture of 4 children on 4/5 trials.

71 Ch will successfully follow the directions: 'get your shoes, sit down, put on your shoes', on 4/5 trials.

73* Ch presented with 5 pictures and asked to show which two pictures are the same. Criterion (Cr) success on 4/5 trials.

78* Ch presented with a series of 4 pictures with missing features which he identifies on 4/5 trials.

82* Ch will indicate which of 4 pictures does not belong in the series (i.e. is not an animal) on 4/5 trials.

86* Ch presented with 3 pictures . Ch points to which of the boxes has 'many' and which has a 'few' buttons. Cr 80% of the time.

87 Ch gives Lot number and name of village 80% of the time.

94* Ch tells the story illustrated by 3 pictures presented in a jumbled order.

95 Ch defines the words: cup, knife and car.

B) Self-Help

5 Ch holds bottle without help while drinking 80% of the time.

8 Ch drinks from a cup, with a minimum of spilling, when held by an adult 80% of the time.
12 Ch takes a spoon filled with food to mouth 80% of the time with adult holding hand lightly.
14 Ch eats food with spoon independently with a minimum of spilling ,80% of the time.
17 Ch sits on potty for one minute.
20 Ch pushes arms through sleeves, legs through pants 80% of the time.
22 Ch takes off shirt when unbuttoned on 4/5 trials.
23 Ch takes off pants when unfastened on 4/5 trials.
26 Ch feeds self using spoon and cup with some spilling on 80% occasions.
31 Ch dries hands without help 80% of the time.
33 Ch controls drooling 90% of the time.
36 Ch brushes his teeth 90% of the time when given a demonstration to copy.
43 Ch will not wet himself during naps 80% of the time.
45 Ch uses kerchief when reminded 80% of the time.
48 Ch unfastens press studs on clothing 80% of the time.
52 Ch finds front of clothing 90% of the time.
60 Ch blows nose when reminded 90% of the time.
63 Ch brushes teeth when given verbal reminder 90% of the time.
65 Ch unbuttons 3 buttons on shirt placed on table on 4/5 trials.
70 Ch can undo buttons on shirt 90% of the time.
72 Ch clears away the dishes from the table on 4/5 trials.
80 Ch buckles and unbuckles belt on shoes on 4/5 trials.
82-86 Cr:80% of the time.
89 Ch laces own shoes on 4/5 trials.
92 Ch indicates clothing appropriate for certain occasions on request.
93 Cr: 80% of the time.
95 Ch prepares own cereal, without making a mess, 80% of the time.

C) **Cognitive**

2 Ch looks for tennis ball, which has been removed from direct line of vision,on 4/5 trials.
4 Ch places a 1" block into a container when shown how to do so on 4/5 trials.
7 Ch can put three 1" blocks into an open container and then empty container.
10 Ch finds a 1" block placed under a cup in child's view with 80% success.
13 Ch places a pencil into a pegboard on a verbal request with 80% success.
15 Ch individually takes out six 1" blocks from a container on 4/5 trials.

16 Ch points to own eye when requested verbally on 4/5 trials.

18* Ch is given 5 pictures and has to show which of the pictures are of the same object, with 80% success.

20 Cr: 90% success.

22* Ch given 3 pictures of a shoe, car, chair and asked to point to the real object with 80% success.

25 Cr: 90% success.

26 Ch completes a 3 piece formboard (8" x 4") comprised of a circle, triangle and square on 4/5 trials.

28 Ch copys a vertical line, the line will be continuous and roughly parallel with the original line.

30 Ch produces a rough copy of a circle, it need not be neatly closed.

32 Ch shown 2 squares and asked to show which is big/small with 90% success.

34 Ch given six 1" squares; 2 red, 2 blue, 2 yellow and is asked to match the same colours. Cr: 90% success.

35 Ch places a 1" block in, on and under a cup on verbal request. Cr: 90% success.

38* Ch shown 3 pictures of children running, eating, and fighting and says what they are doing.Cr: 80% success.

42 Ch points to 10 body parts (eye, nose, ear, mouth, hand, toes, foot, head, fingers, belly) on verbal command with 80% success.

48 Ch is given 3 cups and 3 blocks and is asked to put one block in each cup. Cr: 4/5 trials.

49* Ch is given a picture of 4 boxes, 2 long and 2 short and asked to point to a long and short box. Cr: 4/5 trials.

50* Ch is given 6 pictures (shoe/sock, hammer/nail, bat/ball)in a jumbled order and asked to indicate which objects go together. Cr: 4/5 trials.

52* Ch is given 9 pictures (3 animals, 3 utensils and 3 balls) in a jumbled order and asked to arrange the objects into 3 categories. Cr: 4/5 trials.

57 Ch presented with a sequence of 1 matchbox, 2 buttons and 1 pencil and asked to copy the sequence with the same objects. Cr: 4/5 trials.

61* Ch given a series of 3 pairs of pictures (2 forks, 2 cubes, a comb and a spoon) and asked to say whether the pictures in the pair are the same or different. Cr: 4/5 trials.

64 Ch given the 3 shapes from the formboard: square, triangle and circle and asked to name the shapes.

65 Five 1 cent coins are placed in front of the child, ch asked to pick up from 1 to 5 cents on verbal request. Cr: 80% success.

67 Ch given a picture of a triangle to copy. The triangle should have a recognisable shape . Cr: 4/5 trials.

72 Ch tells what object is removed, when one object is removed from an array of a block, ball, toy car.

Cr: 4/5 trials.

75 Ch given the following on a piece of paper: 3:5 3 6
m: t s m and asked to match the same numbers and letters. Cr: 4/5 trials.

84* Ch given 3 pictures with missing parts, ch names the missing part. Cr: 5/5 trials.

92 Ch presented with 26 lower case letters of the alphabet. Ch asked to name 5 letters.

97 Ch names 20 lower case letters of the alphabet.

98 Ch matches 20 capital and lower case letters.

101* Ch given 2 mazes to complete. Cr: 4/5 trials.

103* Cr: 80% success.

105* Ch sight reads: tree, little, egg, milk, book, school, sit, frog, playing, bun.

D) **Socialisation**

1 Cr: 80% of the time.

2-11 Cr: 70% of the time.

12 Ch will hold and visually examine a new toy for one minute. Cr: 4/5 trials.

13-16 Cr: 70% of the time.

18 Ch will physically and verbally imitate the actions necessary to play peek-a-boo. Cr:70% of the time.

19-21 Cr: 70% of the time.

24 Ch shows a physical response (looking) on hearing own name called on 4/5 trials.

26 Ch physically manipulates a toy on 4/5 trials.

28 Ch physically imitates the movement of another child on 4/5 trials.

30 Ch plays alongside another ch on 4/5 trials.

32 Ch accepts parents absence and will continue their own activity for a minimum of 5 minutes on 4/5 trials.

35-41 Cr: observable as a daily activity.

45 Ch brings common household objects (cup, broom, towel) from another room on verbal direction on 4/5 trials.

51 Ch shows understanding of feelings by putting love, anger and sadness into words. Cr: obs. daily.

52 Cr: obs. weekly.

53 Cr: obs. daily.

54 Cr: 75% of the time.

55 Cr: obs. weekly.

56 Cr: 75% of the time.

58 Cr: obs. daily.

60 Cr: 60% of the time.

62 Cr: 80% of the time.

63 Cr: obs. weekly.

65 Cr: obs. daily.

66 Cr: obs. weekly.

70 Cr: obs. daily.

73 Ch puts his feelings of being angry, happy, sad into words. Obs. daily.
76 Cr: obs. weekly.
77 Cr: obs. daily.
81-83 Cr: obs. weekly.

E) **Motor**

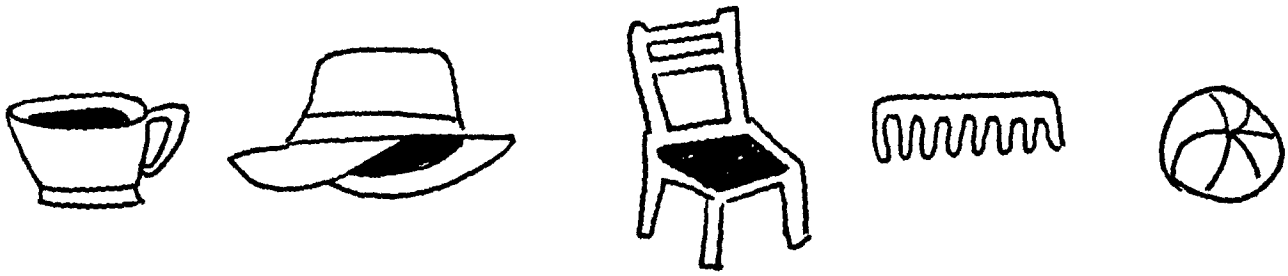
1 Cr: 3/5 trials.
2-5 Cr: 75% of the time.
6-7 Cr: obs. daily.
10-21 Cr: obs. as a daily activity.
22 Ch sits, self supported, for a minimum of 5 minutes. Cr:obs.daily.
23-24 Cr: obs. daily.
26-32 Cr: obs. daily.
33 Ch creeps 2 body lengths. Obs. daily.
35 Ch stands 10 secs with adult barely supporting child's weight. Obs:daily.
38 Ch will empty 1" cubes from an open box on 4/5 trials.
40 Ch scoops up sand with a child's spade on 4/5 trials.
42-43 Cr: obs. daily.
45 Ch takes 4 steps without any support. Obs. daily.
47-49 Cr: obs. daily.
51 Ch removes three 1" pegs from a pegboard on 4/5 trials.
53 Ch builds a tower using three 1" blocks on 4/5 trials.
56 Ch creeps down 5 stairs, feet first, on 4/5 trials.
57-59 Cr: obs. daily.
63 Cr: on 4/5 trials.
64 Ch strings four 1" beads onto a shoe lace in 2 minutes on 4/5 trials.
65-66 Cr: obs. daily.
67 Ch walks down 5 stairs with an adult holding one hand on 4/5 trials.
74-76 Cr: on 4/5 trials.
77 Ch makes balls out of clay on 4/5 trials.
80 Ch bangs five 1" pegs into a pegboard on 4/5 trials.
81 Ch assembles a formboard (4" x 8") with a circle, square and triangle on 4/5 trials.
83-85 Cr: on 4/5 trials.
86-87 Cr: obs daily.
88-89 Cr: obs weekly .
95 Ch cuts along a line for 8", the line will not deviate by more than ¼" from the straight line given,on 4/5 trials.
98 Ch walks a balance beam 6" wide, 1' off the floor without falling on 4/5 trials.
99-101 Cr:4/5 trials.
106 Ch walks down 10 stairs, alternating feet, on 4/5 trials.
113 Ch walks a 6" wide balance beam, forwards, backwards and sideways on 4/5 trials.

118 Cr: obs weekly.
119 Cr: on 4/5 trials.
120 Ch dribbles (by bouncing) a ball with direction on 4/5 trials.
124* Ch given a picture to copy, the reproduction should have 3 key features. Cr: on 4/5 trials.
127 Ch will catch a 4" square bean bag with one hand. Cr: 4/5 trials.
130-131 Cr:4/5 trials.
135-136 Cr: 4/5 trials

* indicates the necessary pictures are supplied,see Appendix V

Illustrations for Portage Checklist

L 17



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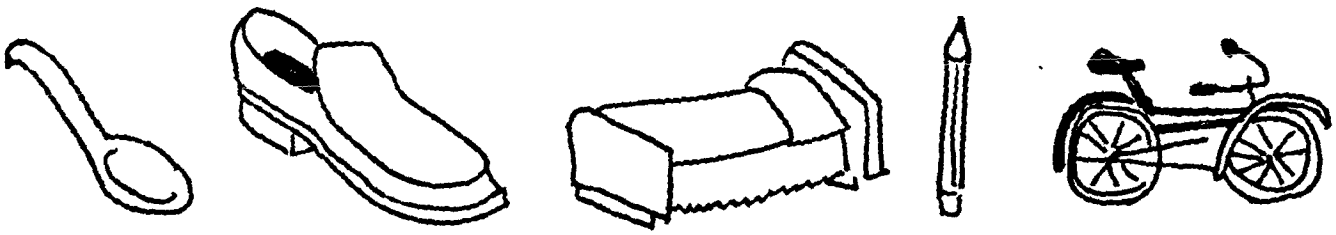

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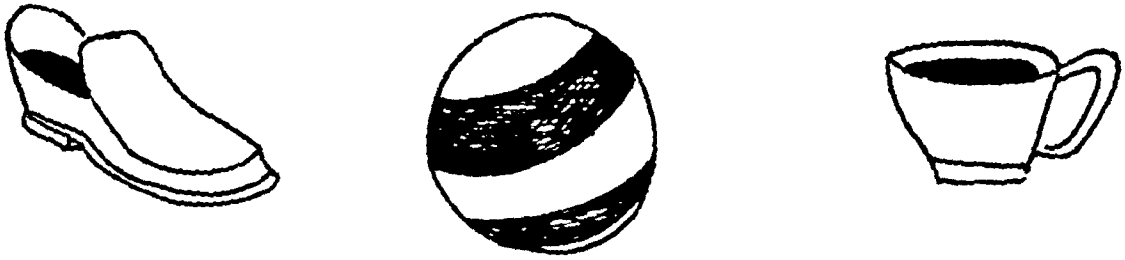

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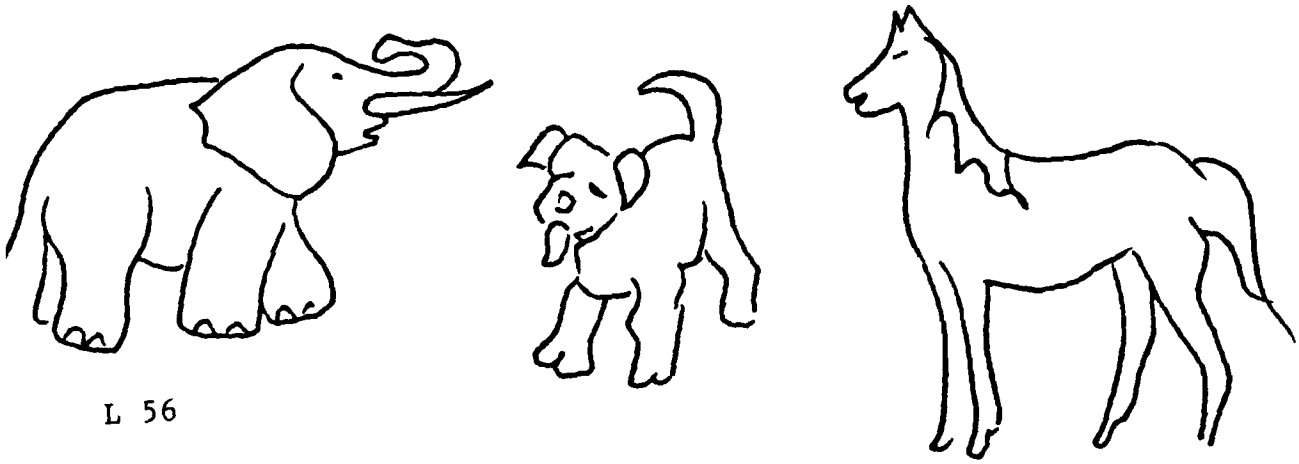

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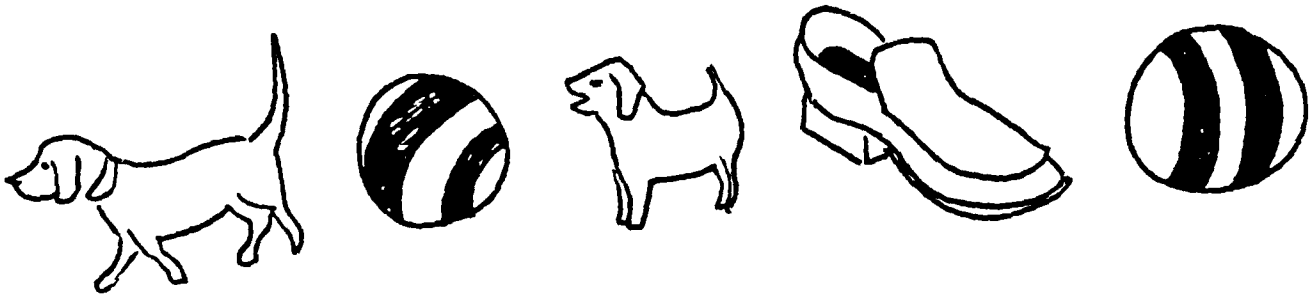

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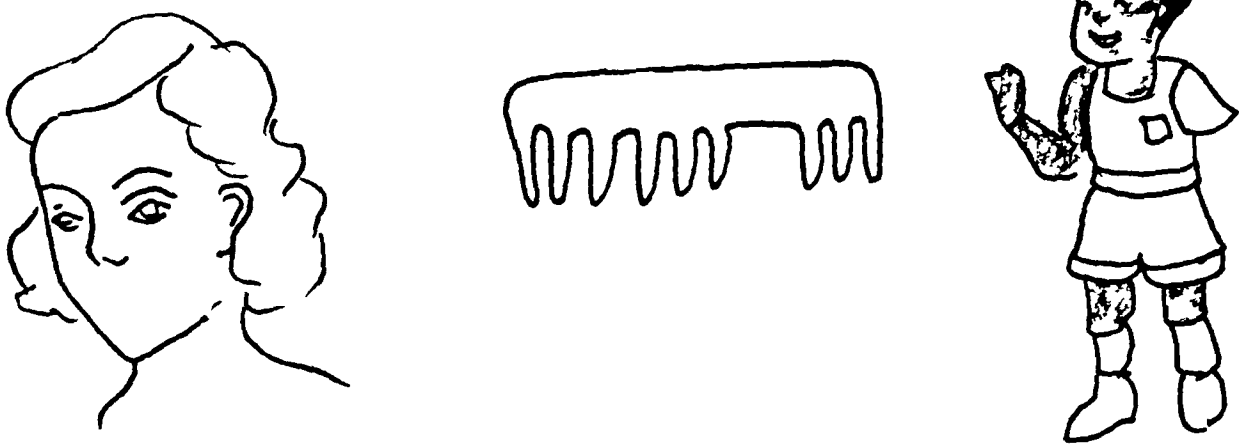

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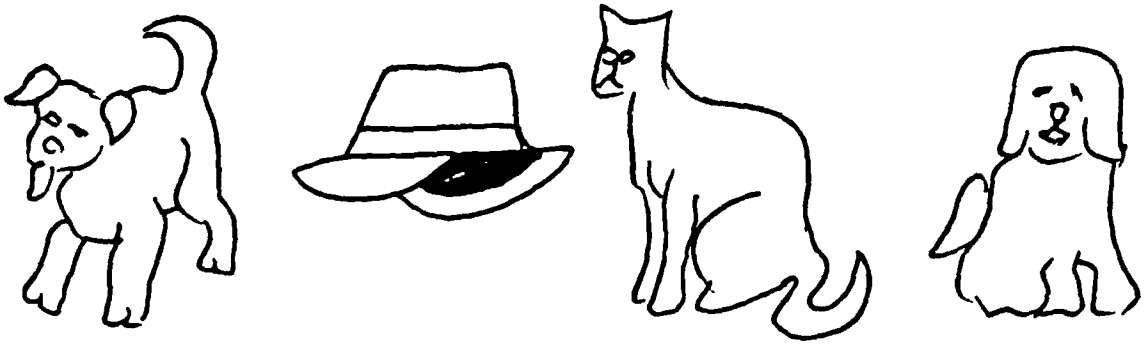

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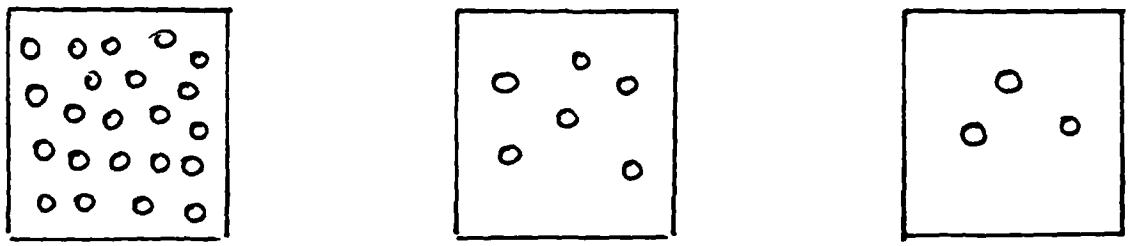

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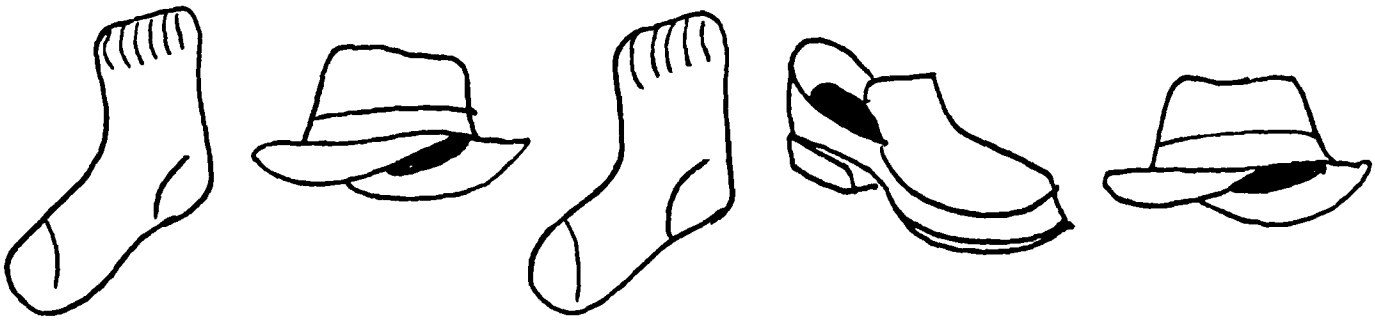

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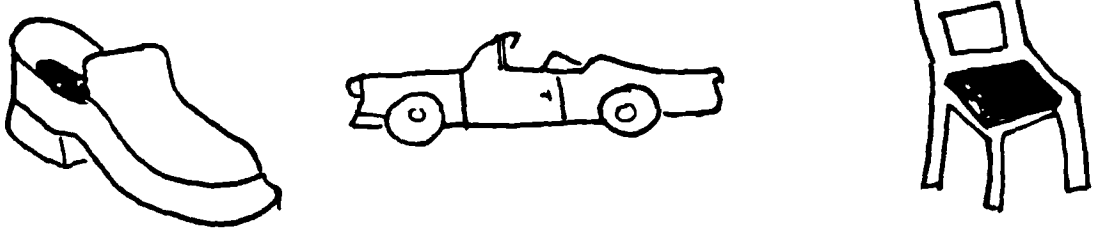

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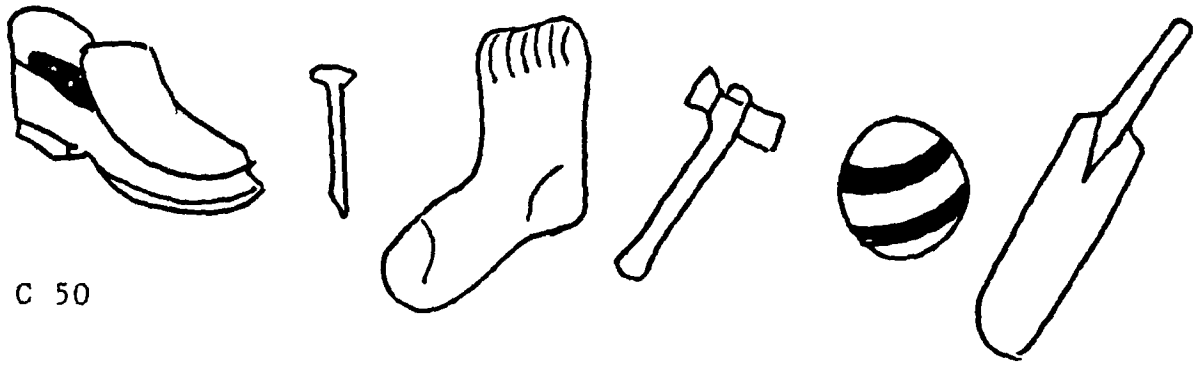

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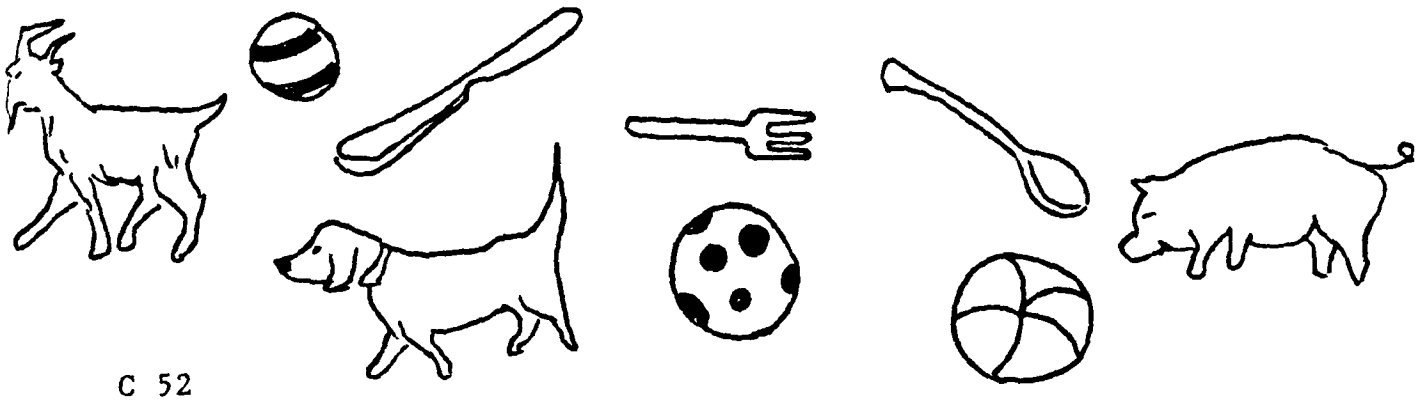

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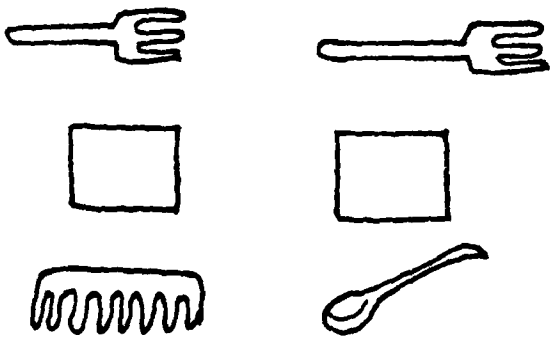

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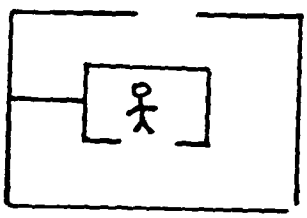
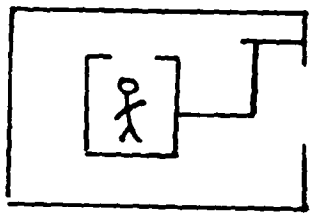


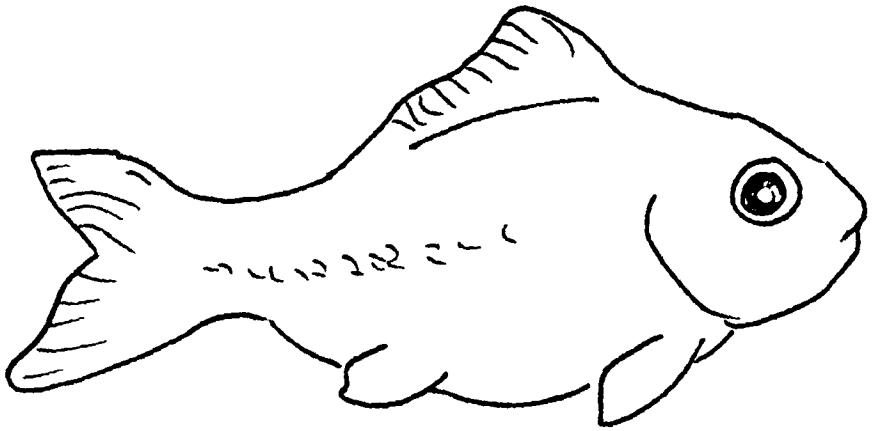


C 101

tree little milk egg book

school sit frog playing bun

C 105



C 124

Appendix VI

Course Outline : Volunteers

Term 1

i) Overview of programme : objectives, methods. *
ii) Introduction to CBR. *
iii) Survey methods : WHO approach. *
iv) Methods of identifying children with disabilities, simple screening methods. *
v) Portage assessment. *
vi) Introduction to children with hearing impairment by Head, School for Deaf. *
vii) Introduction to WHO materials and approach. *
viii) Introduction to children with visual impairment by Head, Unit for the Blind. *
ix) Children with intellectual impairments. *
x) The parent's perspective : Parents' Association for Mentally Retarded Children .
xi) Portage assessment : recalibration . *
xii) Children with movement problems . *
xiii) Personality assessment . *
xiv) The needs of the adult learner : Director of Institute of Adult Education.
xv) Closing session.

Term 2

i) View 'Lets Play', a video-course on nurturing the play of handicapped children by McConkey & Gallagher. *
ii) Portage : recalibration of assessments .*
iii) Parent's perspective : presented by parents of handicapped children.

iv) Preparation of teaching aids. *

v) Teaching and management suggestions for children with speech and hearing problems : presented by Head, School for the Deaf. *

vi) Teaching and management suggestions for children with movement problems . *

vii) Teaching suggestions for children with intellectual problems. *

Term 3

i) Assessing and prioritising the needs of the child and the family .

ii) Selection of appropriate materials from the WHO Manual .

iii) Portage assessment : recalibration. *

iv) Organisation of a panel for the public on the need for community involvement in assisting people with disabilities. *

v) Guidance and Counselling : presented by a Counsellor. *

vi) Public meeting : Community Involvement and Disabled Persons.

vii) Participants on the programme present individual 'cases'. *

viii) Hansen's Disease : Director, Hansen's Disease Programme.

ix) Prevention of disability : District Medical Officer.

Term 4

i) The mobilisation of resources in the community. *

ii) Individual 'case' presentations by participants on the programme. *

iii) Public Meeting.

iv) Evaluation of programme . *

* denotes sessions also given to nursery teachers

Appendix VII

Diary Observations

Introduction: Each person will be asked to keep a diary of what happened on each visit to the child's home. Each entry should be dated. Each person's diary will of course take different approaches, however some of the things you could observe are:

1. Background information

i) description of child: type of disability, how was disability caused and how does the child react to it . Child's personality.
ii) description of mother : attitude to child, personality.
iii) description of father : attitude, involvement, support, personality.
iv) description of other members of the family : reactions, attitudes of siblings, relatives.
v) relationship between mother and father : supportive, stable.
vi) mother-child relationship : how does mother behave with child, does she try and teach the child, does she spend time with the child, does she have a clear idea of what the child can and cannot do?
vii) description of home and environment.
viii) attitudes of neighbours, others in the community.

2. Introduction of CBR Programme

i) how did you begin the CBR training? What area did you choose to focus on?
ii) how do you go about trying to teach the child new skills? What were the reactions/results?

iii) do you think the mother continued the training after you had left the home?

iv) each time you visit please make a note of exactly what happened, where necessary include quotations from mother and child to help illustrate how each visit went.

3. **Reactions to CBR Programme:**

i) how does the child progress on the programme?

ii) how does mother react to the programme? What does she do during your visits and after you leave the home?

iii) reactions of father, others in the home?

iv) what does mother see her role to be in the programme?

v) what do parents see happening in the programme?

vi) has there been a change in the relationship between the parents, between mother and child , father and child or other members of the family and the child?

vii) has the wider community become involved in the programme?

viii) how did attitudes/feelings change during the programme?

4. **Summary:**

At the end the programme could you include a summary of how you feel the programme went, including both the high and low points,the successes and frustrations. Could you evaluate what you think different members of the family gained from the programme and what you learnt/gained as well.

Appendix VIII

Evaluation of programme

We want to know your views about this programme. Please be as honest as you can and do not be afraid of saying what you think. We will not be upset by negative comments.

Organisation of training

1. How suitable were the premises where the programme was conducted (location, facilities, etc.)
2. How suitable were:
   a) time of day
   b) day of the week
   c) length of each session
   d) length of training programme
3. What did you like most about the training programme?
4. What did you dislike most about the training programme?
5. How could the programme be improved?
6. What things should have been covered in the course but were not?
7. What could have been left out of the programme?
8. Was the training programme too long?
9. Was the training at an appropriate level?

Aims of the training programme

10. Do you now have a better idea of what you could expect from the child?
11. Are you noticing more details about children than before?
12. Are you more confident now about helping children?
13. Are you structuring play any more now than before?
14. Are you applying specific techniques in your work with

children now than before?

15. What do you see as the main aim of the programme?

CBR with the families

16. Do you see any improvement in the children you were working with?
17. What impact has the programme had on the mothers?
18. What do the mothers regard as the main aims of the programme?
19. Are other members of the family now more involved in working with the child?
20. Have others commented on changes they have seen in the child?
21. Has the programme affected the community in any way?
22. Which parts of the programme have been difficult to implement?
23. What are the reasons for this?
24. What is the most important aspect of the programme?
25. What is the least important aspect?
26. How helpful were the WHO Manuals?
27. How effective was the supervision you received on the programme?

Summary

28. How helpful was the whole CBR exercise?
29. What, if anything, have you gained from the experience?
30. How realistic do you think it is to help a mother of a disabled child to become a more effective teacher of her child?
31. Have attitudes changed in the community as a result of the project? If so, what evidence do you have for that?
32. How many children is it practical to work with?
33. Would you wish to be involved in another project of this nature in the future?THANK YOU

Appendix IX

Pre-Training Interview For Parents

This interview is being conducted before the training course begins to help us plan future courses.

1. When did you first find out about your child's problem?
2. How were you told and how did you react to the news?
3. What was the reaction of your husband/partner?
4. Was anyone able to help you during this period, how?
5. Can you describe your child's problem?
6. What professional help have you received for the child?
7. How often has such help been available?
8. How valuable was this help when it was available?
9. How confident are you in being able to deal with the child?
10. How do you feel about the future for your child?
11. How would you teach the child a new puzzle?
12. Have you noticed any change in the child over the past 6 months.
13. Who helps you with the child, the father, friends, etc.?
14. How could other members of the family help with the child?
15. What could the community do to help the child?
16. Have you met any other parents of children with problems?
17. How helpful was it meeting them?
18. What are you concerned about regarding your child?
19. What do you hope to get out of this programme?
20. What changes do you hope will result from this programme?
21. Is there anything you would like to add?

THANK YOU

Appendix X

Post-Training Interview for parents

We're conducting this interview at the end of the course to find out what it was like to have been part of the programme and so that we can improve future courses.

1. To what extent was the programme what you expected it would be?

2. To what extent did the things you were concerned about before the course come through?

3. As a result of the course what changes, if any, do you see:
   a) in your child?
   b) in yourself?

4. What role do you feel you played in the training of your child?

5. What are the important parts of the course?

6. Which parts are unimportant?

7. Is there any way that you think the course may affect you in the near future?

8. Do you plan to change anything as a result of the programme?

9. How much time per day did you usually spend on the training activities?

   a) 10 minutes or less.

   b) 10 - 30 minutes

   c) 30 - 60 minutes.

   d) over 1 hour.

10. Did the programme interfere with the other things you have to do in the day?

11. How are CBR activities integrated into the days' activities?

12. What sorts of things did you learn from the programme?

13. Did you get help for the child from other sources over the past year? If so, how helpful were these sources?

14. Have your ideas changed concerning:

    a) what your child is capable of doing?

    b) what progress you can expect from him?

    c) your general expectations of the child?

15. Has your relationship with the child changed as a result of the programme?

16. Have others noticed any changes in the child?

17. If you wanted to help the child learn how to do a puzzle, how would you go about it?

18. Have you met other parents of children with problems over the past year? If so, how helpful was it meeting them?

19. How could other members of your family help with the child?

20. What could the community do to help with the child?

21. How confident are you in being able to deal with the child?

22. How do you feel about the future for the child?

23. How do you get on with the child?

24. Would you prefer to see the LS visit:

    a) every week?

    b) every two weeks?

    c) every month?

25. Did any other member of you family or friends share the teaching of your child?

    a) never c) occasionally

    b) once d) regularly

26. Would you wish the service to continue?

    a) Yes b) No

27. Did you find the service:

    a) not at all helpful?

    b) quite helpful? or

    c) very helpful?

28. If you were asked whether such a programme should be continued and supported, what would you say? What arguments would you give to support your opinion?

29. Thank you. Is there anything you would like to add? We'd be very interested to hear of any other thoughts or feelings you have concerning the programme.

Appendix XI

Six Month Follow-Up Interview for Parents

This interview is being conducted about six months after the training course to find out more about what it was like to have been part of the programme and so that we can improve future courses.

1. What do you think were the main parts of the training programme?

2. What do you remember as the highlight of the programme?

3. What was the low point?

4. Did the course affect you personally in any way?

5. What did you get out of the experience?

6. How, if at all, has your approach to the child changed as a result of the programme?

7. What plans, if any, have you made to change anything or do anything differently as a result of the course?

8. What things, if any, that you learnt from the course have carried over to your life since the programme ended?

9. Who should not be part of a course like this?

10. If you were asked whether such a programme should be continued and supported, what would you say? What arguments would you give to support your opinion?

11. Is there anything you would like to add? We would be very interested to hear your thoughts regarding the programme.

THANK YOU

Appendix XII

Health Questionnaire

Name of LS: Code No.:
Name of child: Date:

Please ring the correct answer

1.	Do you often have back-ache?	Yes	No
2.	Do you feel tired most of the time?	Yes	No
3.	Do you often feel miserable or depressed?	Yes	No
4.	Do you often have bad headaches?	Yes	No
5.	Do you often get worried about things?	Yes	No
6.	Do you usually have difficulty falling asleep?	Yes	No
7.	Do you wake unnecessarily early in the morning?	Yes	No
8.	Do you wear yourself out worrying about yourself?	Yes	No
9.	Do you often get into a violent rage?	Yes	No
10.	Do people often annoy and irritate you?	Yes	No
11.	Have you ever had a twitching of the face?	Yes	No
12.	Do you sometimes become scared for no good reason?	Yes	No
13.	Are you scared to be alone?	Yes	No
14.	Are you easily upset or irritated?	Yes	No
15.	Are you frightened of meeting people?	Yes	No
16.	Are you constantly keyed up and jittery?	Yes	No
17.	Do you suffer from indigestion?	Yes	No
18.	Do you often suffer from an upset stomach?	Yes	No
19.	Is your appetite poor?	Yes	No
20.	Does every little thing get on your nerves?	Yes	No
21.	Does your heart often race like mad?	Yes	No
22.	Do you often have bad pains in your eyes?	Yes	No
23.	Have you ever had a nervous breakdown?	Yes	No

THANK YOU

Appendix XIII

Self Rating Scale

Name of LS: Code No.:
Name of child: Date:

Instructions: "Here is a list of words with their opposites. Between each of the pairs of words are the numbers 1 to 5. Think of yourself in terms of each pair of words in turn and then put a circle around one of the numbers. The more you think one end of the scale applies to you, the nearer to that end you circle the number. Be careful not to miss out any of the pairs of words."

Practice Items:

Tall	1 2 3 4 5	Short
Weak	1 2 3 4 5	Strong
Good natured	1 2 3 4 5	Irritable
Worried	1 2 3 4 5	Calm
Unsure of myself	1 2 3 4 5	Confident
Helpless	1 2 3 4 5	In control
Depressed about N	1 2 3 4 5	Happy about N
Not enjoying N	1 2 3 4 5	Enjoying N
N and I don't have fun together	1 2 3 4 5	N and I have lots of fun together
Ill at ease with N	1 2 3 4 5	Comfortable with N
Find it hard to show warmth to N	1 2 3 4 5	Easy to show warmth to N
Ashamed of N	1 2 3 4 5	Proud of N
N seems an unhappy child	1 2 3 4 5	N seems a happy child
Don't know how much to expect of N	1 2 3 4 5	Know how much to expect of N
Not seeing any progress in N	1 2 3 4 5	Seeing progress in N
Pessimistic re N's future	1 2 3 4 5	Optimistic re N's future
Not able to share my worries re N	1 2 3 4 5	Able to share my worries re N
Nobody is interested	1 2 3 4 5	Many interested
Afraid to ask questions about N	1 2 3 4 5	Confident in asking questions re N
Don't trust experts	1 2 3 4 5	Trust experts

Appendix XIV

Child Rating Scale

Name of LS: Code No.:
Name of child: Date:

Instructions: we would like to get a better idea of how parents see their children and the children of others. Look at the list of words below. Take each word separately and use it to complete the sentence.

Key: 1: never 2: sometimes 3: half the time 4: frequently
5: always

i) **rate your own child**: the first statement is aggressive, you decide how true that is of your child using the key above.
My child is:

aggressive	1 2 3 4 5
annoying	1 2 3 4 5
anxious	1 2 3 4 5
calm	1 2 3 4 5
confident	1 2 3 4 5
considerate	1 2 3 4 5
cruel	1 2 3 4 5
demanding	1 2 3 4 5
destructive	1 2 3 4 5
fearful	1 2 3 4 5
friendly	1 2 3 4 5
hostile	1 2 3 4 5
nervous	1 2 3 4 5
patient	1 2 3 4 5
selfish	1 2 3 4 5
timid	1 2 3 4 5
well-mannered	1 2 3 4 5

Key: 1: never 2: sometimes 3: half the time 4: frequently
5: always

ii) **What I would like my child to be:** the first statement is aggressive, you decide how aggressive you would like your child to be.

I wish my child was:

aggressive	1 2 3 4 5
anxious	1 2 3 4 5
annoying	1 2 3 4 5
calm	1 2 3 4 5
confident	1 2 3 4 5
considerate	1 2 3 4 5
cruel	1 2 3 4 5
demanding	1 2 3 4 5
destructive	1 2 3 4 5
fearful	1 2 3 4 5
friendly	1 2 3 4 5
hostile	1 2 3 4 5
nervous	1 2 3 4 5
patient	1 2 3 4 5
selfish	1 2 3 4 5
timid	1 2 3 4 5
well-mannered	1 2 3 4 5

Key: 1: never 2: sometimes 3· half the time 4: frequently
5: always

iii) **Rate what most children are like**: the first is aggressive, how aggressive do you think most children are.
Most children are:

aggressive	1 2 3 4 5
annoying	1 2 3 4 5
anxious	1 2 3 4 5
calm	1 2 3 4 5
confident	1 2 3 4 5
considerate	1 2 3 4 5
cruel	1 2 3 4 5
demanding	1 2 3 4 5
destructive	1 2 3 4 5
fearful	1 2 3 4 5
friendly	1 2 3 4 5
hostile	1 2 3 4 5
nervous	1 2 3 4 5
patient	1 2 3 4 5
selfish	1 2 3 4 5
timid	1 2 3 4 5
well mannered	1 2 3 4 5

Appendix XV

Sentence Completion Questionnaire

Name of LS: Code No.:
Name of child: Date:

Would you be kind enough to complete each of the following sentences.

A. 1. When I think of N I...

2. The thing I still don't understand about my child's problem is...

3. The thing most parents find hardest to accept about their handicapped child is...

4. When I first learnt my child was disabled I...

5. My husband's reaction to N is...

B. 6. The greatest difficulty for my child is...

7. My child becomes most easily upset when...

8. When my child comes home he wants most to...

9. When the child's brothers and sisters ask about him I say...

10. The way my other children treat N is...

11. The way N treats my other children is...

12. The thing I'd like to see my community do for the handicapped is...

13. When people know you have a disabled child they...

14. I do/don't feel free to discuss my child's difficulty with neighbours because...

15. When I think of my child's future, I...

16. Although my child has some difficulty I would like him to...

Appendix XVI

Observations of Local Supervisors by Independent Evaluators

Name of IE: Code No.:
Name of LS: Date:

i) Brief description of task LS was presenting:

ii) Brief description of any aids used in the session:

iii) Most positive feature of training session:

iv) Most negative feature of training session:

Rate the following statements using the key:

1. strongly agree
2. agree
3. uncertain
4. disagree
5. strongly disagree

v) LS appeared confident 1 2 3 4 5

vi) LS appeared to have a good rapport with
a) mother 1 2 3 4 5
b) child 1 2 3 4 5

vii) LS prepared a definite activity for the session 1 2 3 4 5

viii) The material prepared for the child was at an appropriate level 1 2 3 4 5

ix) LS aware their task was to train the mother to be more effective in their interaction with the child rather than taking full responsibilty for the child themselves 1 2 3 4 5

x) LS had a clear appreciation of the child's particular disability 1 2 3 4 5

xi) Portage assessment was done effectively 1 2 3 4 5

xii) LS adopts a clear structure in presenting the task to the mother 1 2 3 4 5

xiii) LS appeared to be involved in the task 1 2 3 4 5

General assessment of the session: please circle one:

1. very good
2. good
3. uncertain
4. poor
5. very poor

Please give reasons to justify the assessment you made:

Appendix XVII

Economic and Social Statistics on Guyana

Source: 'The State of the World's Children: 1987' UNICEF, Oxford University Press

a) Demographic Indicators

i) Total population/child population (0 - 4 years) (millions) 1985: 0.9/0.1

ii) % of population urbanised 1985: 32%

iii) Ethnic composition

East Indian	51.8%
African	31.2%
Mixed	10.3%
Amerindian	4.9%
Portuguese	0.8%
Chinese	0.4%
European	0.3%

iv)	Infant mortality rate (annual number of deaths of infants under one year of age per 1,000 live births)	1960: 69	1985:	33
v)	Under 5 mortality rate (annual number of deaths of children under 5ys of age per 1,000 live births)	1960: 94	1985:	41
vi)	Crude death rate (annual number of deaths per 1,000 population)	1960: 10	1985:	6
vii)	Crude birth rate (annual number of births per 1,000 population)	1960: 42	1985:	27
viii)	Life expectancy at birth	1960: 60	1985:	69

b) Health and Nutrition

i) % of mothers breast feeding 1981/1984
3mths: 64/77% 6mths: 48/60% 12mths 21/35%

ii) % of population with access to drinking water
1980/1983: 72/80%

iii) % of one year old children fully immunised 1980/1985
TB: 68/77% DPT: 35/57% Polio: 42/56%

iv) % of infants with low birth weight (under 2,500 grams)
1985: 18%

c) Education

i) Adult literacy rate (% of population, over 15 ys, who can read and write)
male/female: 1970: 94/88 1985: 97/95

ii) % of age group enrolled in primary school
male/female: 1982: 96/95 1985: 99/99

iii) % of grade 1 enrolment completing primary school
1982: 84% 1984: 97%

d) Economic indicators

i) GNP per capita: 1982 US$ 670 1984 US$ 590

ii) rate of inflation: 1970-1982 9.9%

iii) Official Development Assistance (ODA) inflow, 1982 US$ 38 million

iv) ODA as % of recipient GNP, 1981 7%

Appendix XVIII

Screening Test

Ask the household head the following questions about all the members of the home.

1. Does any person have difficulty seeing?
2. Does any person have difficulty hearing?
3. Does any person have difficulty in talking?
4. Does any person act strangely in your home?
5. Does any person have difficulty in moving?
6. Does any person have fits?
7. Does any person have difficulty in learning?
8. Do any of the children seem to be slow?
9. Do any of the children have serious delays in sitting, standing or walking?
10. Does the child learn to do things like other children his/her age?

"YEAR OF STANDING UP FOR GUYANA"

Appendix XIX

MINISTRY OF EDUCATION

Cable Address: "MINED"

P. O. Box 1014,
Georgetown,
Guyana.

IN REPLYING QUOTE DATE HEREOF AND No.....

1986-04-21

TO WHOM IT MAY CONCERN

This letter serves to introduce Cde Brian O'Toole Lecturer of the University of Guyana and Student of University of London. He wishes to carry out Research "Community-Based Rehabilitation with Pre-School Disabled Children in Guyana"

The Ministry of Education has granted permission for him to carry this project.

Kindly afford Cde O'Toole the usual co-operation which will enable him to complete his programme.

Thanks.

Chief Education Officer
Ministry of Education

Daphne D. Persico (Dr)
CHIEF EDUCATION OFFICER.

THE UNIVERSITY OF GUYANA

BOX 101110, GEORGETOWN.
TELEPHONE 54841 - 9

FROM: Director, I.A.C.E.

TO: Mr Brian O'Toole, Lecturer,
Faculty of Education

DATE: March 5, 1986

SUBJECT: Approval of Special Education Course

I have read the draft course outline - Children with Special Needs: A Community Based Rehabilitation Approach. It promises to be an interesting one.

A decision should be made early about location of the community, the venue for training and other logistics.

I approve of the course and wish you success.

Samuel A. Small

:gs

Sunday CHRONICLE 50c.

No. 3196 1988-10-05

Teaching volunteers to help the disabled

THE Institute of Adult and Continuing Education (IACE), has ventured into yet another aspect of community education, this time to teach volunteers how to use effective and yet simple methods of rehabilitation in helping children with disabilities, especially in rural areas.

This takes the form of a one-year Extra-Mural Programme, beginning this month for the East Bank, Demerara from Agricola to Craig.

The programme aims to teach people how to help children with difficulties in the following areas: vision, hearing and speaking, learning, movement and behaviour problems.

It will be held twice a week, from 17:00 hrs. to 19:00 hrs. (5-7 p.m.) and a major part of it will be practical sessions with children who have such problems. Resource persons on the programme will include doctors, social workers, physiotherapists, specialist teachers and psychologists.

The programme is open to all those who have an interest in the area of children with disabilities. Parents and guardians of such children especially, can learn how they can help their children at home and what services are available to them within their respective communities.

The course is free and anyone can register by telephoning 64987 of by visiting the IACE in the Queen's College compound.

Additional registration forms are available from either Geraldine Maison-Halls, Physiotherapy Department, Georgetown Hospital or Brian O'Toole, Faculty of Education, University of Guyana.

An introductory session for anyone interested in this programme will be held at St. Anne's Primary School, Agricola, on October 14 at 17:30 hrs. (5.30 p.m.).

Guyana CHRONICLE 50¢

No.:3533 WEDNESDAY, 1987-10-14

Survey of disabled persons in Grove

Participants on the IACE-sponsored Community-Based Rehabilitation Programme, in collaboration with the Grove / Diamond Health Committee, are planning to carry out a house-to-house survey in Grove on Sunday October 18. The survey is to identify persons with disabilities.

The Community-Based Rehabilitation Programme has now been operating for one year on the East Bank, Demerara. Twenty volunteers from the communities on the East Bank have been trained to work with persons with disabilities. A very successful three-day workshop was organised by the participants for the parents of disabled children in the Grove area in August. The parents were keen to ensure the programme continues.

The survey Sunday will be carried out by members of the Community-Based Rehabilitation Programme, members of the Grove / Diamond Health Committee and, teachers and parents of disabled children.

Sunday $1 CHRONICLE

No. 3426 1997-05-31

Efforts of voluntary organisations important to our development

President Hoyte tells seminar for mentally handicapped

BY COLIN KING

PRIVATE citizens and voluntary organisations have a vital role to play in extending to the mentally handicapped the "human touch" which Government agencies may not provide, President Desmond Hoyte said yesterday.

"Voluntary organisations are very important, and Government's policy is to encourage as many such organisations as possible in all manner of work, including caring for the disadvantaged," he said.

Cde Hoyte was delivering the opening address to a seminar on "The Mentally Handicapped — A Citizen," organised by the Georgetown Association for the Mentally Handicapped, (GAMH) to coincide with National Disability Awareness week. A large cross-section of the community was present at the opening of the one-day seminar at the Nurses Association Hall on Alexander Street.

Welcoming the gathering, which included Vice President Viola Burnham, Minister Stella Odie-Ali, and Special Adviser to the President, Dr. P.A. Reid, GAMH President Maylene Saul said membership of the association is open to all who feel able to help the mentally handicapped.

The handicapped cannot achieve their full potential without help, she said, thus the decision to form the association, which now comprises mostly parents of the mentally handicapped.

Referring to several misconceptions which have tended to impede work with the mentally handicapped, Cde Saul said: "They need love and care, not to be shut away and forgotten."

Yesterday's seminar, which included a solo rendition of the song "Youths are important to Guyana" and a martial arts display both involving students of the David Rose Centre, included also two presentations on "The Mentally Handicapped-A Citizen" by Dr Frank Williams, and "sexuality and the mentally handicapped" by Doreen Richardson of the Guyana Responsible Parenthood Association. Workshop discussions followed the presentations.

Participants in the working sessions included representatives of voluntary and other groups working with the disabled or disadvantaged in different areas of the country, the University of Guyana, the School of Nursing, and the Bel Air Lions among others.

"I believe that the quality of a society is best judged by the care and concern which that society shows for its members who are disadvantaged," President Hoyte told the gathering.

Mental illness is very complex, the need for a humane approach to the matter has been recognised as more and more has been learnt over the years. The seminar was timely, Cde Hoyte said, since there are many misconceptions about mental illness.

It is important, he said, to build public awareness that the mentally handicapped are citizens, with citizens' rights, they are human beings in need of the help of society, and are persons who can make a contribution to society.

There is need to ensure there is an ongoing programme to educate people as to how they can help the mentally handicapped and on the nature of mental handicap. More specialised training should also be conducted to increase the number of workers available to give support to relatives in the treatment of the handicapped.

'The Communicator' June 10th 1987

Novel approach to disability

"CHILDREN with special needs — a community-based rehabilitation approach." That's the title of a new community outreach programme that is being conducted at Agricola, East Bank, Demerara by the Institute of Adult and Continuing Education (IACE).

Programme Co-ordinator, Lynette Anderson said that the approach being taken in this programme is a novel one. It deals with disabled children in a way which will help parents realise that instead of hiding the children's' problems they should seek professional assistance.

The course, now in its second term, is being held twice weekly for one year. Parents from the community learn how to use effective and yet simple methods of rehabilitation. The newly-acquired skills will enable parents to make life happier for children with difficulties in seeing, hearing, speaking and learning, and moving around. After the volunteer has been trained, he is required to pass on the knowledge to another member of the family.

Sessions are co-ordinated by Education Psychologist, Mr. Brian O'Toole of the Faculty of Education, and Senior Physiotherapist of the Georgetown Hospital, Geraldine Maison-Halls.

In stressing the importance of this course, Cdn. Anderson pointed out that it will address the [illegible] of handicapped children and their parents on the Lower East Bank, Demerara . It is also directed at an evaluation of The World Health Organisation's Model for Community Base rehabilitation.

The Director of IACE, Mr. Samuel Small holds the view that people are ashamed to send their children with disabilities to obtain normal schooling. Therefore, he feels that this course is a step in the right direction. According to him, kids with disabilities are not given a chance to cope properly with society. It is hoped, that through this course, parents will get the necessary confidence to send their children to regular school."

Guyana Chronicle Tuesday, 1987-08-02

HELPING DISABLED KIDS

A public meeting to discuss ways of helping disabled children will be held this Thursday at 5.30pm. at St Anne's Primary School, Agricola.

The meeting has been planned by participants of the Community Based Rehabilitation Programme organised by the Institute of Adult and Continuing Education.

Speakers at the meeting will include representatives from the Ministry of Health, Ministry of Education, the Guyana Commission for the Disabled and the Faculty of Education, University of Guyana.

Mothers' responses to Sentence Completion Questionnaire

No. Item	'Volunteer'(VM) Pre N=26 %	N	'Volunteer'(VM) Post N=20 %	N	'Nursery'(NM) Pre N=23 %	N	'Nursery'(NM) Post N=20 %	N
1. When I think of N I...								
feel depressed	38%	10	15%	3	9%	2	15%	3
worried	12%	3	15%	3	35%	8	5%	1
concerned re future	19%	5	5%	1				
not worried, grow out of it			10%	2	30%	7		
seen improvements			45%	9			30%	6
normal			10%	2			30%	6
other	19%	5			9%	2		
no response (N/R)	12%	3			17%	4	20%	4
2. The thing I don't understand...								
causation	54%	14	30%	6	35%	8	25%	5
why my child?	8%	2			4%	1	10%	2
child has no problems			5%	1	13%	3	5%	1
how improve child's behaviour			10%	2				
no problems			30%	6				
other	31%	8	25%	5	17%	4	15%	3
N/R	8%	2			30%	7	30%	6
3. The thing most difficult to accept.								
people gossiping	15%	4					5%	1
why me	12%	3			13%	3		
I accept child for what he is	12%	3			13%	3	15%	3
doesn't look handicapped	8%	2	5%	1				
they won't ever be normal	12%	3						
child can't do anything	12%	3	5%	1	13%	3		
causation			15%	3	17%	4	30%	6
child's behaviour			45%	9				
other	15%	4	25%	5	22%	5	25%	5
N/R	15%	4	5%	1	22%	5	25%	5
4. When I heard N was handicapped I..								
astonished	23%	6	15%	3	9%	2	5%	1
upset, sad	35%	9	50%	10	39%	9	10%	2
sought help	4%	1	5%	1			15%	3
accepted it	8%	2	10%	2			40%	8
child doesn't have problems			10%	2	26%	6	5%	1
hoped for a miracle	12%	3						
other			5%	1			5%	1
N/R	19%	5	5%	1	26%	6	20%	4

No. Item	VM				NM			
	Pre		Post		Pre		Post	
5. My husband's reaction to N is...								
get help	4%	1	5%	1				
worried, sad, confused	23%	6	15%	3	9%	2	5%	1
same as me	12%	3	5%	1	4%	1		
accepting, calm, loving	15%	4	20%	4	9%	2	5%	1
very helpful	4%	1					5%	1
child will grow out of it			10%	2	22%	5	40%	8
not concerned			5%	1			5%	1
single parent	12%	3	25%	5	22%	5	15%	3
other					13%	3		
N/R	31%	8	15%	3	22%	5	25%	5
6. The greatest problem for N is...								
child has no difficulty	4%	1	5%	1	4%	1	15%	3
movement	19%	5	20%	4				
communicating	19%	5	20%	4	48%	11	25%	5
hearing	15%	4	5%	1	9%	2		
learning	12%	3	15%	3	9%	2	15%	3
eating	8%	2			4%	1	10%	2
behaviour	4%	1			9%	2	5%	1
fits	4%	1					5%	1
everything			10%	2			5%	1
dressing			10%	2			5%	1
N/R	15%	4	15%	3	17%	4	15%	3
7. My child becomes upset when he's..								
teased	19%	5	35%	7	17%	4	30%	6
can't get what he wants	23%	6	20%	4	9%	2	25%	5
frustrated by his disability	8%	2	5%	1			5%	1
left on his own	8%	2			4%	1	5%	1
punished			5%	1	26%	6	5%	1
hungry			15%	3				
other	23%	6	15%	3	30%	7	10%	2
N/R	19%	5	5%	1	13%	3	20%	4
8. When he comes home he wants to ..								
eat	35%	9	35%	7	13%	3	5%	1
play	23%	6	35%	7	65%	15	55%	11
sleep							15%	3
other	23%	6	15%	3	9%	2	10%	2
N/R	19%	5	15%	3	13%	3	15%	3
9. When the other children ask about him, I say...								
he'll catch up later	23%	6	10%	2	4%	1	15%	3
he needs their love	12%	3	5%	1	22%	5	5%	1
God made her that way	8%	2						
what her problem is	27%	7	65%	13	9%	2		
they accept her as she is	8%	2	5%	1	22%	5	30%	6
N/R	23%	6	15%	3	43%	10	50%	10

No.	Item	VM Pre		VM Post		NM Pre		NM Post	
10.	The way my other children treat N is...								
	just like the others	77%	20	85%	17	61%	14	60%	12
	they bully her					9%	2	10%	2
	don't play with her	4%	1						
	not applicable	4%	1	5%	1	17%	4	20%	4
	N/R	15%	4	10%	2	13%	3	10%	2
11.	The way N treats my other children is...								
	bad	8%	2	5%	1	13%	3	15%	3
	just like the others	69%	18	80%	16	52%	12	50%	10
	not applicable(N/A)	4%	1			17%	4	20%	4
	N/R	19%	5	15%	3	17%	4	15%	3
12.	The thing I'd like to see my community do to help is...								
	give them help in any way	62%	16	20%	4	48%	11	50%	10
	establish special school	23%	6	75%	15	30%	7	35%	7
	other			5%	1	9%	2		
	N/R	15%	4			13%	3	15%	3
13.	When people know you have a disabled child, they								
	gossip	46%	12	35%	7	61%	14	50%	10
	are surprised	12%	3						
	supportive, sympathetic	19%	5	55%	11	22%	5	30%	6
	shun you	8%	2						
	some laugh, some help			10%	2				
	N/R	15%	4			17%	4	20%	4
14.	I do/don't feel free to discuss my child...								
	No: they only gossip	31%	8	10%	2	22%	5	15%	3
	No: hurts too much	4%	1						
	No: embarrassed	15%	4			13%	3	15%	3
	Yes: not ashamed	15%	4	45%	9	22%	5	15%	3
	Yes: get new ideas	15%	4	20%	4	22%	5	45%	9
	other	4%	1	20%	4	4%	1		
	N/R	15%	4	5%	1	17%	4	10%	2
15.	When I think of N's future								
	hopeful	15%	4	55%	11	43%	10	50%	10
	depressed	50%	13	30%	6	35%	8	20%	4
	other	8%	2			4%	1	10%	1
	N/R	27%	7	15%	3	17%	4	20%	4
16.	I'd like N to								
	lead a normal life	12%	3	15%	3	9%	2	20%	4
	be independent	15%	4	10%	2	4%	1	40%	8
	other	73%	19	75%	15	87%	20	40%	8

Appendix XXVI

Mothers' responses to Pre-Training Interview

No.	Item	'Volunteer' Mothers(VM) N=26 %	N	'Nursery' Mothers(NM) N=23 %	N
1.	When I found out about the child's problem				
	0-1 ys	62%	16	22%	5
	1-2 ys	15%	4	13%	3
	2-3 ys			22%	5
	3 ys	19%	5	9%	2
	at nursery school			9%	2
	because of CBR programme	4%	1		
	N/R			26%	6
2.	How were you told...				
	realised problem myself	23%	6	48%	11
	told by doctor	46%	12	13%	3
	told by teacher			26%	6
	other	20%	5		
	N/R	12%	3	13%	3
3.	What was the reaction of your partner...				
	blamed me	8%	2		
	worried, upset	19%	5	17%	4
	accepted child	12%	3	13%	3
	little interest	23%	6	4%	1
	optimistic	8%	2	22%	5
	other	4%	1	9%	2
	N/A	4%	1	17%	4
	N/R	23%	6	17%	4
4.	a) Did anyone help you at this time...				
	Yes	27%	7	13%	3
	No	58%	15	61%	14
	N/R	15%	4	26%	6
	b) How did they help...				
	went to special centre for assessment	12%	3		
	financial help	4%	1		
	medical help	4%	1		
	caretaking help	8%	2	13%	3
5.	What is the child's problem...				
	no idea	35%	9	13%	3
	general idea	31%	8	35%	8
	slow developer	12%	3	39%	9
	N/R	23%	6	13%	3

No.	Item	VM		NM	
6.	What professional help have you received ..				
	physiotherapy	12%	3	4%	1
	special school	4%	1	4%	1
	clinic for medical	23%	6	13%	3
	surgery	4%	1		
	none	46%	12	65%	15
	N/R	12%	3	13%	3
7.	How often has such help been available..				
	monthly clinics	23%	6	13%	3
	every 3 months	12%	3		
	just once	8%	2	9%	2
	N/A	58%	15	78%	18
8.	How valuable was the help given...				
	very helpful	15%	4	9%	2
	of some value	15%	4	4%	1
	limited value	12%	3	9%	2
	N/A	58%	15	78%	18
9.	How confident are you with the child				
	highly confident	4%	1	35%	8
	confident	46%	12	30%	7
	low confidence	27%	7	13%	3
	other	12%	3	9%	2
	N/R	12%	3	13%	3
10.	How do you feel re the future for N ..				
	highly confident*	15%	4	17%	4
	confident	31%	8	35%	8
	low confidence **	31%	8	22%	5
	other	23%	6	9%	2
	N/R			17%	4

* she has a bright future despite the disability...my child will overcome the difficulties...she will be someone in the future

** feel very depressed...feel inadequate and confused

11.	How would you teach a puzzle to N...				
	demonstration	54%	14	30%	7
	verbal explanation			43%	10
	don't know (D/K)	27%	7	22%	5
	N/R	19%	5	4%	1

No.	Item	VM		NM	
12.	Seen any improvements in last 6 mths				
	limited	54%	14	65%	15
	none	31%	8	35%	8
	worse	12%	3		
	N/R	4%	1		
13.	Who helps you with N				
	child's brother/sister	15%	4	9%	2
	child's father	31%	8	17%	4
	child's grandparents	15%	4	22%	5
	everyone in the home	12%	3	17%	4
	no one	27%	7	22%	5
	N/R			13%	3
14.	How could other relatives help				
	general assistance *	38%	10	13%	3
	specific help **	50%	13	48%	11
	N/R	12%	3	39%	9
	* in whatever way they can..give advice..show kindness				
	** physical exercises..teach sign language..help with feeding..help with dressing				
15.	What could the community do to help				
	general help	15%	4	13%	3
	show kindness, accept him	12%	3	17%	4
	nothing	23%	6	9%	2
	establish a special unit	15%	4	9%	2
	make professional help available			4%	1
	D/K	19%	5	13%	3
	N/R	15%	4	35%	8
16.	Have you met other parents of disabled children...				
	Yes	38%	10	35%	8
	No *	50%	13	48%	11
	N/R	12%	3	17%	4
	* never considered it..afraid of what others would say				
17.	How helpful was it meeting with other parents...				
	very helpful *	23%	6	26%	6
	some help	8%	2	4%	1
	unhelpful, they have their own problems	8%	2	4%	1
	* learn from one another..share ideas.. see children worse off than mine..I'm not the only one with the problem				

No.	Item	VM		NM	
18.	What are you concerned about re N...				
	he will become normal	31%	8		
	good education	23%	6	30%	7
	help child with her disability	15%	4	9%	2
	get him into a special school	8%	2		
	communicate better			17%	4
	all-round development			22%	5
	other	4%	1	4%	1
	N/R	19%	5	17%	4
19.	What do you hope to get out of programme...				
	child to communicate better	8%	2	22%	5
	do better generally	31%	8	22%	5
	get some help for my child	23%	6	9%	2
	act like a normal child	4%	1	13%	3
	put into practice what I learn	12%	3		
	get child into a special school	12%	3	13%	3
	N/R	12%	3	22%	5
20.	What changes in N do you hope will come about ...				
	change in a specific area *	42%	11	39%	9
	change in general **	23%	6	26%	6
	become normal	15%	4		
	D/K	12%	3	17%	4
	N/R	8%	2	17%	4

* walk by herself..speak more clearly
use her hand properly

** help her do better..learn something
change her behaviour

Appendix XXVII

Mothers' responses to Post-Training Interview

No.	Item	'Volunteer' Mother(VM) N=20 %	N	'Nursery Mother(NM) N=18 %	N
1.	To what extent were you satisfied with the programme...				
	highly satisfied	55%	11	39%	7
	satisfied	10%	2	28%	5
	unsatisfied	5%	1	22%	4
	other	15%	3	6%	1
	N/R	15%	3	6%	1
2.	Did the programme respond to your concerns				
	very much	20%	4		
	good	40%	8	44%	8
	satisfactory	10%	2	17%	3
	unsatisfactory	10%	2	17%	3
	had no concerns	20%	4	11%	2
	other			6%	1
	N/R			6%	1
3.a)	What changes do you see in your child...				
	change noted	100%	20	67%	12
	no change noted			22%	4
	N/R			10%	2
	change: improved academic skills	5%	1	6%	1
	happier	15%	3		
	improved communication	10%	2	44%	8
	more independent	25%	5	6%	1
	more mobile	15%	3	6%	1
	more motivated	20%	4	6%	1
	better behaved	10%	2		
3.b)	What changes do you see in yourself...				
	change noted	100%	20	50%	9
	no change seen			28%	5
	N/R			22%	4
	change: more relaxed	30%	6	22%	4
	proud of child	15%	3		
	happier	20%	4	11%	2
	more confident	10%	2	11%	2
	think of child more now	10%	2		
	more aware of what N can do	10%	2	6%	1
	know how to help N	5%	1		

No.	Item	VM		NM	
4.	What role did you play in the programme..				
	very important role	80%	16	72%	13
	not involved	5%	1	17%	3
	other	5%	1	6%	1
	N/R	10%	2	6%	1
5.	What are the important parts of the programme...				
	everything	30%	6	56%	10
	academic skills	10%	2		
	movement training	20%	4		
	feeding	10%	2		
	speech training			11%	2
	other	15%	3	6%	1
	N/R	15%	3	28%	5
6.	Which parts are unimportant...				
	none	100%	20	100%	18
7. & 8.	Not understood by mothers				
9.	How long spent on programme daily...				
	10 min	10%	2	6%	1
	10-30 min	25%	5	39%	7
	30-60 min	40%	8	11%	2
	1 hr	15%	3	22%	4
	N/R	10%	2	22%	4
10.	Did programme interfere with other responsibilities...				
	No	90%	18	83%	15
	N/R	10%	2	17%	3
11.	How are CBR activities integrated into daily activities...				
	didn't interfere with daily activities	45%	9	50%	9
	special time allocated	10%	2		
	teaching integrated into other tasks	20%	4		
	other	10%	2	22%	4
	N/R	15%	3	28%	5
12.	What did you learn from the programme...				
	understand N better	10%	2		
	increased knowledge	15%	3	17%	3
	how to teach N	40%	8	44%	8
	become closer to N	10%	2		
	how to get help for N	10%	2		
	nothing			11%	2
	other	5%	1	17%	3
	N/R	10%	2	11%	2

No.	Item	VM		NM	
13.	a) Did you get help from other sources over the past year...				
	Yes	45%	9	11%	2
	No	55%	11	89%	16
	b) How valuable was that help...				
	very helpful	100%	9/9	100%	2/2
14.	Have your ideas changed concerning...				
	a) What N is capable of				
	Yes	65%	13	56%	10
	No	25%	5	17%	3
	a little			11%	2
	N/R	10%	2	17%	3
	b) What you could expect from him...				
	Yes	65%	13	56%	10
	No	20%	4	17%	3
	a little			11%	2
	N/R	15%	3	17%	3
	c) Your general expectations of N...				
	Yes	60%	12	50%	9
	No	20%	4	22%	4
	a little			6%	1
	N/R	20%	4	22%	4
15.	Has your relationship with N changed...				
	Yes *	65%	13	39%	7
	No	15%	3	39%	7
	N/R	20%	4	22%	4
	* understand each other better..better co-operation..improved communication.. closer now..more aware				
16.	Have others noted changes in N ...				
	Yes	90%	18	72%	13
	No	5%	1	22%	4
	N/R	5%	1	6%	1
17.	How would you teach N to do a puzzle...				
	by demonstration	20%	4	44%	8
	physical help	10%	2		
	verbal help	10%	2	28%	5
	combination of physical, verbal, prompting and feedback	35%	7	17%	3
	other	10%	2		
	N/R	15%	3	11%	2

No.	Item	VM		NM	
18.	a) Have you met parents of other disabled children over the past year...				
	Yes	70%	14	44%	8
	No	20%	4	39%	7
	N/R	10%	2	17%	3
	b) How helpful was the meeting...				
	valuable	57%	8/14	63%	5/8
	no help	14%	2/14	25%	2/8
	other	14%	2/14	13%	1/8
	N/R	14%	2/14		
19.	How could relatives help you with N...				
	feeding, dressing, bathing	15%	3		
	help with school work	20%	4		
	play with N	10%	2		
	teach N	5%	1	56%	10
	be more patient	15%	3	17%	3
	they help already	10%	2		
	speech training	15%	3	6%	1
	no one helps			6%	1
	N/R	10%	2	17%	3
20.	How could the community help with N...				
	establish a special centre	40%	8	22%	4
	mobility training	10%	2		
	help with school work	15%	3		
	couldn't do anything	5%	1	11%	2
	other	15%	3	34%	6
	N/R	15%	3	34%	6
21.	How confident are you in being able to help N...				
	very confident	75%	15	78%	14
	uncertain	10%	2	11%	2
	N/R	15%	3	11%	2
22.	How do you feel about the future...				
	very confident	45%	9	67%	12
	hopeful	20%	4	11%	2
	uncertain	20%	4	22%	4
	N/R	15%	3		
23.	How do you get on with the child...				
	good relationship	65%	13	61%	11
	satisfactory relationship	25%	5	28%	5
	N/R	10%	2	11%	2

No.	Item	VM		NM	
24.	How often would you prefer the LS visit...				
	weekly	70%	14	56%	10
	fortnightly	10%	2	33%	6
	monthly	20%	4	11%	2
25.	Did any other family member help with the teaching...				
	never	10%	2	28%	5
	occasionally	40%	8	17%	3
	regularly	50%	10	56%	10
26.	Should the programme be continued...				
	Yes	100%	20	100%	18
27.	How would you evaluate the service...				
	not at all helpful				
	quite helpful	15%	3	28%	5
	very helpful	85%	17	72%	13
28.	What arguments are there in support of the programme...				
	helps N	35%	7	78%	14
	helps integrate children	15%	3	6%	1
	helps parents	15%	3	6%	1
	other	15%	3		
	N/R	20%	4	11%	2

Appendix XXVIII

Mothers' responses to Follow-Up Interview Schedule

No.	Item	'Volunteer' Mother (VM) N=16 %	N	'Nursery' Mother (NM) N=14 %	N
1.	What were the main parts of the course				
	training of the child	50%	8	57%	8
	regular visits to the child	19%	3	14%	2
	visits by co-ordinators	19%	3		
	showing parents how to help the child	13%	2	28%	4
2.	What was the highlight of the course...				
	general training of the child	38%	6	50%	7
	integration of child into society	44%	7	14%	2
	help for the parents	13%	2	14%	2
	make child more independent	6%	1	14%	2
	other			7%	1
3.	What was the low point...				
	none	88%	14	50%	7
	irregular visits *	13%	2	43%	6
	no response by the child			7%	1
	* no improvements seen because of the irregular visits...people only come to ask questions				
4.	Question not understood				
5.	What did you get out of the experience...				
	learn need for patience	13%	2	7%	1
	how to deal with the child generally *	44%	7	50%	7
	how help others in such a situation	19%	3	7%	1
	know what to expect from the child	13%	2	14%	2
	self confidence	13%	2		
	nothing **			14%	2
	other			7%	1
	* learnt how deal with child in a better manner..teach her the things she should know				
	** I haven't gained anything because I don't know what's going on				
6.	How has your approach changed...				
	more relaxed	31%	5	43%	6
	confident about the future	44%	7	7%	1
	not changed	19%	3	29%	4
	N/R	6%	1	21%	3

No.	Item	VM		NM	
7.	What plans do you have to change anything				
	get medical help for N	19%	3		
	get child into special school/unit	25%	4	14%	2
	get child into regular school	19%	3		
	N/R	38%	6	86%	12
8.	What things, if any, that you learnt from the course have influenced your life...				
	how to care for disabled children *	25%	4	21%	3
	not to get depressed	19%	3	21%	3
	learnt to be more patient	19%	3	14%	2
	learnt how to help others	13%	2	14%	2
	other	13%	2	7%	1
	nothing	13%	2	21%	3
	* I learnt how to learn and how to help the handicapped....I learnt how to deal with my child better...now I understand her difficulties				
9.	Who should not be part of the programme.				
	everyone should take part	100%	16	57%	8
	not people with normal children			43%	6
10.	Should the programme be continued...				
	Yes	100%	16	100%	14
	why? helps the disabled	25%	4	43%	6
	helps the parents *	19%	3	29%	4
	can now share ideas with others	13%	2	21%	3
	other	44%	7	7%	1
	* many parents feel the child will never overcome the problem, this programme helps remove some of these ideas				
11.	Anything you would like to add...				
	continue the programme *	13%	2	14%	2
	open a unit for the disabled	38%	6	7%	1
	visit more often			36%	5
	N/R	50%	8	43%	6
	* publicise programme more so others can benefit..you've shown keen interest in my child.. the programme should reach the whole of Guyana..it's given me very different feelings for my child.				

Griffiths scores, pre,post and follow-up for Nursery sample

Ch.	Griffiths Subtest																				
	A			B			C			D			E			F			GQ		
	Pre	Pt	FU	Pre	Pt	FU	Pre	Pt	FU	Pre	Pt	FU	Pre	Pt	FU	Pre	Pt	FU	Pre	Pt	FU
32	67	90	94	63	90	93	67	71	76	77	67	82	67	71	76	76	75	82	70	77	84
33	87	91	92	78	81	84	70	76	70	78	88	89	70	77	79	74	77	78	76	79	82
34	110	104	110	90	95	106	76	73	68	90	85	97	71	81	74	76	88	77	86	86	89
35	90	94	100	59	77	109	47	55	74	75	77	77	78	77	71	59	68	86	68	75	86
36	73	81	76	86	81	81	54	62	60	54	68	67	54	60	60	51	68	68	62	70	69
37	72*			81			88			84			72			86			80		
38	116	106	104	105	106	99	2	4	6	81	91	107	60	82	77	34	29	21	66	70	70
39	105	94	91	78	83	83	58	49	47	61	63	86	54	63	60	78	74	73	72	71	73
40	71	74	81	58	60	77	52	68	72	55	71	84	52	58	59	45	60	64	56	65	73
43	120	105	116	88	89	101	72	86	81	68	75	84	68	75	78	88	79	87	84	85	91
46	123*	116		100	91		73	105		77	95		82	102		82	91		90	100	
47	88	84	103	74	90	103	77	87	95	74	99	111	77	70	95	81	96	82	78	88	98
48	104	95	102	88	81	88	75	88	90	79	81	80	75	75	78	92	81	92	86	84	88
52a	98	97	99	68	69	93	57	50	51	53	53	56	60	56	51	57	63	59	66	65	68
52b	95*	87		77	87		82	84		86	87		73	80		77	98		82	87	
53	112*			105			12			112			91			37			78		
54	44	61	55	57	70	82	39	40	51	60	72	72	39	40	44	47	61	59	48	57	60
55	88	89	110	102	96	116	78	81	103	88	96	110	84	74	87	88	85	97	88	87	104
58	104*	92		81	86		65	55		73	86		65	68		62	71		74	76	

* moved Pre: pre test Pt: Post-test FU: Follow-up

Griffiths scores, pre, post and follow-up for Volunteer sample

Ch	Griffiths Subtest																				
	A			B			C			D			E			F			GQ		
	Pre	Pt	FU	Pre	Pt	FU	Pre	Pt	FU	Pre	Pt	FU	Pre	Pt	FU	Pre	Pt	FU	Pre	Pt	FU
2a	84	88	88	84	86	80	48	56	70	61	64	65	45	50	55	45	52	60	61	66	70
2b	30	34	40	76	80	74	58	72	64	55	49	48	42	51	52	53	72	74	52	59	59
3	82	82	94	67	74	83	52	54	66	63	64	57	54	56	64	64	68	62	64	66	71
4*	105			76			11			65			80			37			63		
5	74	79	82	83	77	80	61	64	65	70	71	74	63	64	67	69	64	68	70	70	73
6	79	82	89	90	94	89	79	82	78	83	84	87	81	81	82	93	92	89	84	86	86
8a	108	113	112	96	93	98	2	3	4	76	83	86	80	77	82	39	33	38	67	67	70
8b*	74			84			63			95			61			66			74		
9a	26	34	55	24	21	21	26	20	25	30	33	32	29	27	27	27	27	29	27	27	32
10a	83			94			92			89			71			94			87		
10b	94	90	96	58	52	60	64	57	66	56	55	60	39	52	58	61	64	70	62	62	68
12	81	82	83	67	55	64	5	4	6	55	58	60	61	70	72	34	29	34	50	50	53
13	28	30	27	50	57	61	34	34	34	53	63	59	48	49	48	43	47	57	43	47	48
14	62	71	65	70	73	76	56	49	61	32	41	43	20	34	38	45	46	52	48	52	56
15	38	50	72	60	60	72	9	9	10	54	89	90	65	79	84	34	31	29	43	53	60
18	72	81	81	72	69	63	45	44	49	47	47	46	49	47	46	52	50	46	56	56	55
19a*	67			23			21			21			16			21			28		
19b	16	20	19	25	27	33	25	27	29	14	16	18	23	24	26	22	28	26	21	24	25
22	16	19	24	22	25	26	13	19	20	24	27	24	19	29	36	19	24	26	19	24	28
26*	55	56		38	39		24	24		36	38		26	28		36	38		36	37	
30a	75	93	104	63	89	96	72	77	86	72	80	86	72	82	87	72	96	98	72	86	93
31a	48	56	62	42	54	56	27	31	29	26	39	39	21	35	35	30	33	31	33	41	42
31b	56	61	63	78	86	88	78	78	80	78	82	80	68	78	78	77	78	82	73	77	79

* moved or died Pre: Pre test Pt: Post-test FU: Follow-up

Appendix XXXI

N=1 Analysis of Portage Scores

Explanation of table:

Portage area: M= Motor Soc= Socialisation S/H= Self-Help
L= Language C= Cognitive

Condition Length: number of data points in baseline (A), and treatment (B).

Trend Direction: the celeration line for A and B is calculated. If the trend is increasing an acceleration line (/) is drawn, if decreasing a deceleration line is drawn (\),and no change is represented (=). This is calculated for conditions A and B and noted in column 1. In the box underneath a note is made whether the trend is increasing (+), decaying (-), or no change ( ).

The criterion is that improvement should be seen over the AB period, if so an * is printed in the box.

Trend Stability: change in trend direction should conform to a 15% stability criterion to judge whether the data is sufficiently stable to provide a convincing demonstration of experimental control when experimental conditions are changed. 15% of the highest data points in A is calculated, an envelope is drawn around the condition A trend line which represents the acceptable stability criterion, the same is done for condition B. The percentage of data points which fall within the trend stability range is then calculated. If 85% or more of the data points fall within the stability range, 'S' (stable) is entered in column ii of the table, if less than 85%, 'V' (variable) is entered.

The criterion is that stability should be seen in A and B, if this is the case an * is printed in the appropriate box in column ii.

Level Change: the scores on the first and last day for A and B are noted. An improvement is indicated (+), deterioration (-) and no change ( ). The ordinate value of the first and last data point of condition A is identified. The smaller value is subtracted from the larger value and a note made of whether the change is in the direction of improvement (+), deterioration (-), or whether there is no change ( ). This information is entered in column iii of the table.

The criterion is that improvement should be seen across conditions, if so an * is printed in the appropriate box in column iii.

Absolute Change in Level: the change in level from condition A to B is noted and inserted in column iv of the table. The smaller value is subtracted from the larger value and a note is made whether there is improvement (+), deterioration (-) or no change in level ( ).

The criterion is that there should be improvement across conditions, if so an * is printed in the appropriate box in column iv.

Percentage of overlap: the range of values in A and the number of data points in B which fall within the range of A is noted. The number of data points of B which fall within the range of A is divided by the total number of data points in B and multiplied by 100 and inserted in column v.

The criterion is that the percentage of overlap between A and B should be no more than 5%, if so an * is printed in column v of the table.

Significance: for a result to be judged significant the criterion should be satisfied in four out of the previous five conditions, in such a case an * is printed in the column headed 'significance'.

N=1 analysis of Portage scores for children working with Volunteers

Child	Portage area	Condition length[1] A	B	i)change in trend direction	ii)change in trend stability	iii)change in level	iv)absolute change in level	v)percentage of overlap	signif.
2a	Motor	4	7	(=) (+)	S/100 S/100	71/71 73/86	(71-86) +15	0%	5/5
				*	*	*	*	*	*
	Social.	12	7	(=) (+)	S/100 S/100	54/58 60/67	(58-67) +9	0%	5/5
				*	*	*	*	*	*
2b	Self-Help(SH)	6	5	(+) (+)	S/100 S/100	78/84 88/96	(84-96) +12	0%	4/5
				( )	*	*	*	*	*
3a	Language	6	5	(=) (+)	S/100 S/100	8/8 10/16	(8-16) +8	0%	5/5
				*	*	*	*	*	*
	Social.	11	7	(+) (+)	S/100 S/100	31/33 34/39	(33-39) +6	0%	4/5
				( )	*	*	*	*	*
4a	S/H	5	5	(=) (+)	S/100 S/100	70/70 71/78	(70-78) +8	0%	5/5
				*	*	*	*	*	*
5a	Cognitive	4	3	(+) (+)	S/100 S/100	79/81 82/88	(81-88) +7	0%	4/5
				( )	*	*	*	*	*
	Social.	7	4	(+) (+)	S/100 S/100	70/75 76/81	(75-81) +6	0%	3/5
				( )	*	( )	*	*	
6a	Language	4	4	(-) (+)	S/100 S/100	83/83 84/89	(83-89) +6	0%	5/5
				*	*	*	*	*	*
	Social.	8	2	(+) (+)	S/100 S/100	71/76 78/80	(76-80) +4	0%	3/5
				( )	*	( )	*	*	
8a	Social.	5	5	(+) (+)	S/100 S/100	44/49 50/56	(49-56) +7	0%	3/5
				( )	*	( )	*	*	
8b	Language	4	5	(+) (+)	S/100 S/100	61/62 67/71	(62-71) +9	0%	4/5
				( )	*	*	*	*	*

Child	Portage area	Condition length[1] A	B	i)change in trend direction	ii)change in trend stability	iii)change in level	iv)absolute change in level	percentage overlap	signif.
8b	Language	4	5	(+) (+) ( )	S/100 S/100 *	61/62 67/71 *	(62-71) +9 *	0% *	4/5 *
9a	Motor	4	8	(+) (+) ( )	S/100 S/100 *	26/27 28/42 *	(27-42) +15 *	0% *	4/5 *
10a	Language	4	3	(+) (+) ( )	S/100 S/100 *	70/72 75/80 *	(72-80) +8 *	0% *	4/5 *
10b	Cognitive	4	4	(+) (+) ( )	S/100 S/100 *	40/41 42/46 *	(41-46) +5 *	0% *	4/5 *
11	Motor	4	3	(=) (+) *	S/100 S/100 *	6/6 6/7 ( )	(6-7) +1 ( )	33% ( )	2/5
12a	Cognitive	4	3	(=) (=) *	S/100 S/100 *	18/18 20/23 *	(18-23) +5 *	0% *	5/5 *
13b	Social.	4	8	(=) (+) *	S/100 S/100 *	42/42 43/59 *	(42-59) +17 *	0% *	5/5 *
14a	Language	4	6	(+) (+) ( )	S/100 S/100 *	49/50 52/60 *	(50-60) +10 *	0% *	4/5 *
	Cognitive	10	6	(+) (+) ( )	S/100 S/100 *	32/37 38/46 *	(37-46) +9 *	0% *	4/5 *
15a	Cognitive	5	6	(+) (+) ( )	S/100 S/100 *	24/26 26/38 *	(26-38) +12 *	0% *	4/5 *
	Motor	11	7	(+) (+) ( )	S/100 S/100 *	73/78 80/90 *	(78-90) +12 *	0% *	4/5 *
18a	Language	4	5	(+) (+) ( )	S/100 S/100 *	44/45 46/54 *	(45-54) +9 *	0% *	4/5 *
	Social.	9	3	(+) (+) ( )	S/100 S/100 *	59/63 66/67 ( )	(63-67) +4 *	0% *	3/5 *

Child	Portage area	Condition length[1] A	B	i)change in trend direction	ii)change in trend stability	iii)change in level	iv)absolute change in level	percentage overlap	signif.
19a	Language	5	4	(+) (+) ( )	S/100 S/100 *	34/35 35/38 *	(35-38) +3 *	25%	3/5
19b	Cognitive	7	5	(+) (+) ( )	S/100 S/100 *	17/19 22/29 *	(19-29) +10 *	0% *	4/5 *
22a	Language	5	5	(=) (+) *	S/100 S/100 *	5/5 8/10 *	(5-10) +5 *	0% *	5/5 *
	Cognitive	11	5	(+) (+) ( )	S/100 S/100 *	16/19 21/32 *	(19-32) +13 *	0% *	4/5 *
26a	Social.	4	4	( ) ( ) ( )	S/100 S/100 *	10/13 14/18 ( )	(13-18) +5 *	0% *	3/5
30a	Motor	8	7	(=) (+) *	S/100 S/100 *	24/24 25/35 *	(24-35) +11 *	0% *	5/5 *
30b	Motor	4	5	(+) (+) ( )	S/100 S/100 *	19/20 22/32 *	(20-32) +12 *	0% *	4/5 *
31a	Cognitive	6	6	(+) (+) ( )	S/100 S/100 *	19/21 22/29 *	(21-29) +8 *	0% *	4/5 *
	Social.	12	8	(+) (+) ( )	S/100 S/100 *	39/44 46/54 *	(44-54) +10 *	0% *	4/5 *
31b	Social.	6	4	(+) (+) ( )	S/100 S/100 *	31/52 54/56 ( )	(52-56) +4 *	0% *	3/5
	Cognitive	10	3	(+) (+) ( )	S/100 S/100 *	32/36 38/42 ( )	(36-42) +6 *	0% *	3/5

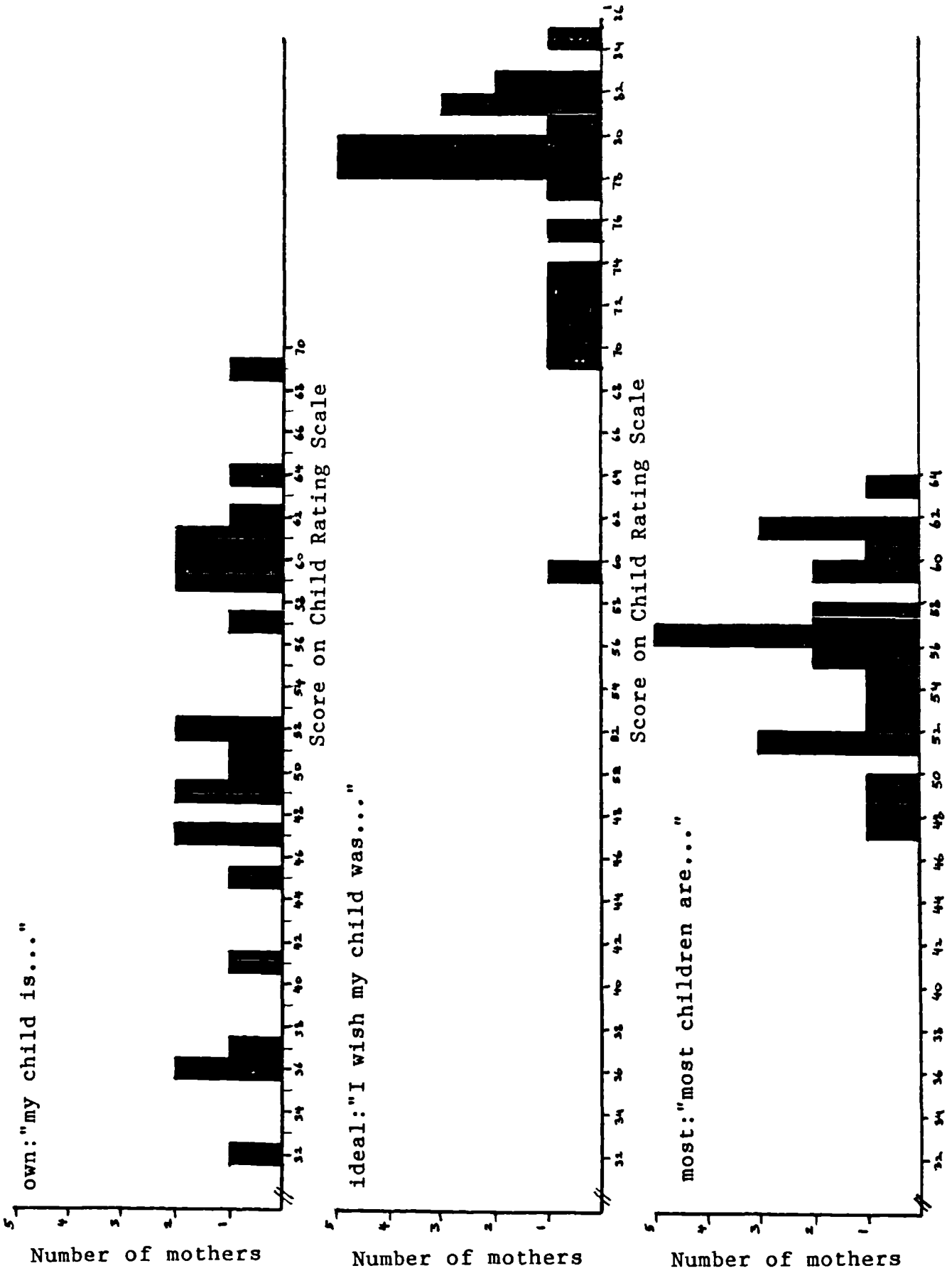
1 Condition length: number of data points in baseline (A) and treatment (B).

N=1 analysis of Portage scores for children working with Nursery Teachers

Child	Portage area	Condition length A	Condition length B	i)change in trend direction	ii)change in trend stability	iii)change in level	iv)absolute change in level	v)percentage overlap	signif.
32	Language	4	6	(+) (+) ( )	S/100 S/100 *	44/46 48/56 *	(46-56) +10 *	0% *	4/5 *
	Social.	10	6	(+) (+) ( )	S/100 S/100 *	51/57 59/70 *	(57-70) +13 *	0% *	4/5 *
33	Cognitive	4	4	(=) (+) *	S/100 S/100 *	32/32 34/42 *	(32-42) +10 *	0% *	5/5 *
	Self-help	8	5	(+) (+) ( )	S/100 S/100 *	62/66 67/70 ( )	(66-70) +4 *	0% *	3/5
34	Language	4	5	(+) (+) ( )	S/100 S/100 *	38/40 42/47 *	(40-47) +7 *	0% *	4/5 *
	Cognitive	9	5	(+) (+) ( )	S/100 S/100 *	19/23 26/33 *	(23-33) +10 *	0% *	4/5 *
35	Language	4	7	(+) (+) ( )	S/100 S/100 *	34/35 36/47 *	(35-47) +12 *	0% *	4/5 *
	Cognitive	11	8	(+) (+) ( )	S/100 S/100 *	61/63 66/74 *	(63-74) +11 *	0% *	4/5 *
36	Language	4	4	(+) (+) ( )	S/100 S/100 *	43/44 46/57 *	(44-57) +13 *	0% *	4/5 *
	Cognitive	8	5	(+) (+) ( )	S/100 S/100 *	48/50 52/57 *	(50-57) +7 *	0% *	4/5 *
38	Cognitive	3	4	(+) (+) ( )	S/100 S/100 *	24/25 30/38 *	(25-38) +13 *	0% *	4/5 *
	Social.	8	4	(+) (+) ( )	S/100 S/100 *	51/54 55/61 *	(54-61) +7 *	0% *	4/5 *

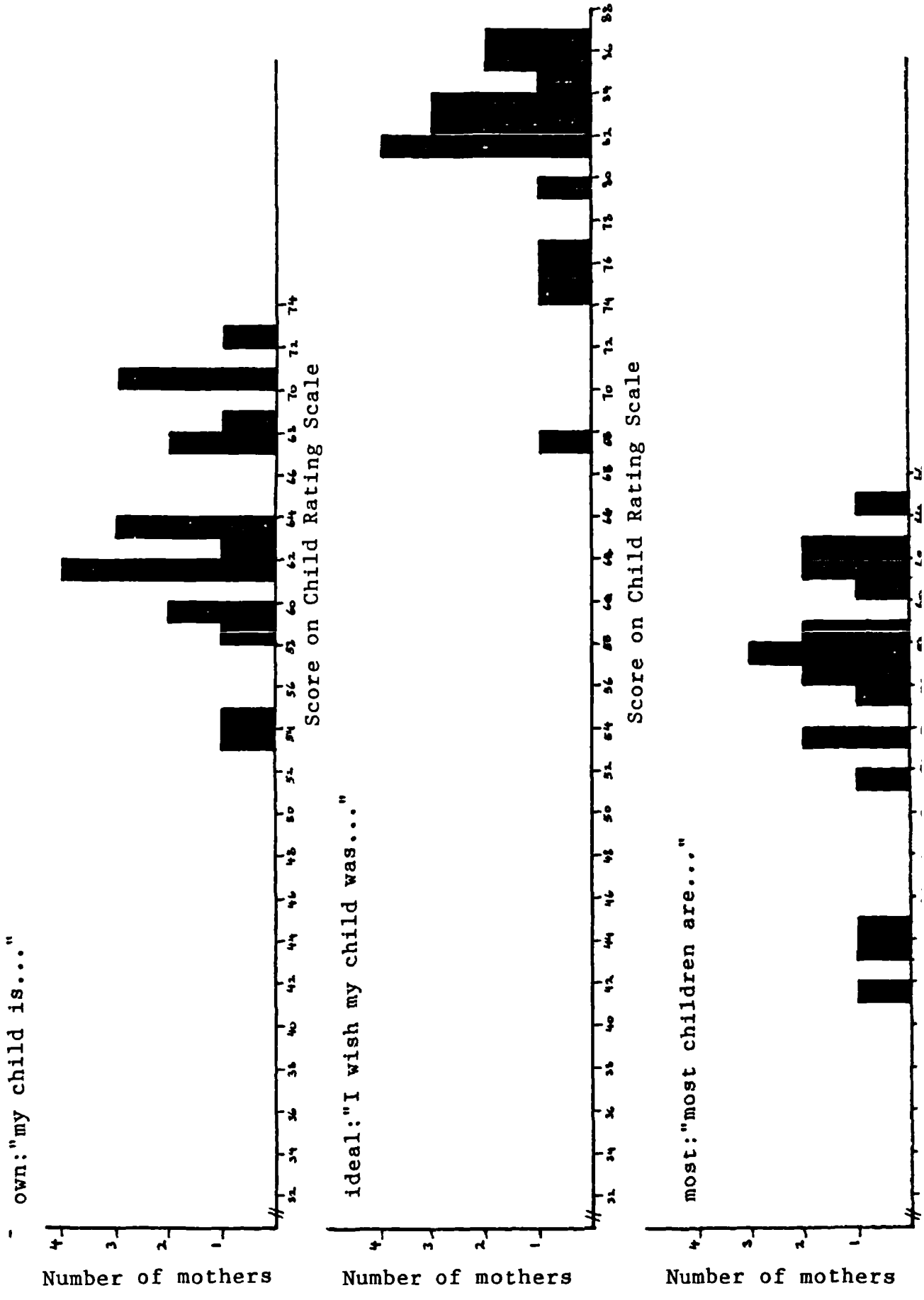
Child	Portage area	Condition length A	B	i)change in trend direction	ii)change in trend stability	iii)change in level	iv)absolute change in level	percentage overlap	signif.
39	Language	4	4	(+) (+)	S/100 S/100	40/41 42/45	(41-45) +4	0%	4/5
				( )	*	*	*	*	*
	Social	8	2	(+) (+)	S/100 S/100	48/51 52/56	(51-56) +5	0%	3/5
				( )	*	( )	*	*	
40	Language	4	5	(+) (+)	S/100 S/100	39/40 41/47	(40-47) +7	0%	4/5
				( )	*	*	*	*	*
	Cognitive	9	6	(+) (+)	S/100 S/100	22/26 28/34	(26-34) +8	0%	4/5
				( )	*	*	*	*	*
43	Language	4	4	(+) (+)	S/100 S/100	41/42 44/50	(42-50) +8	0%	4/5
				( )	*	*	*	*	*
	Cognitive	8	4	(+) (+)	S/100 S/100	28/33 34/37	(33-37) +4	0%	3/5
				( )	*	( )	*	*	
52a	Cognitive	5	5	(+) (+)	S/100 S/100	24/27 27/38	(27-38) +9	20%	3/5
				( )	*	*	*	( )	
52b	Cognitive	4	5	(+) (+)	S/100 S/100	28/30 32/40	(30-40) +10	0%	4/5
				( )	*	*	*	*	*
	Social.	9	4	(+) (+)	S/100 S/100	52/56 58/65	(56-65) +9	0%	4/5
				( )	*	*	*	*	*
54	Cognitive	4	5	(+) (+)	S/100 S/100	27/28 30/38	(28-38) +10	0%	4/5
				( )	*	*	*	*	*
55	Language	4	2	(+) (+)	S/100 S/100	62/65 66/67	(65-67) +2	0%	2/5
				( )	*	( )	( )	*	
58	Language	4	3	(+) (+)	S/100 S/100	36/37 38/42	(37-42) +5	0%	4/5
				( )	*	*	*	*	*

Distribution of ratings on the Child Rating Scale for 'Volunteer' Mothers - Pre Test



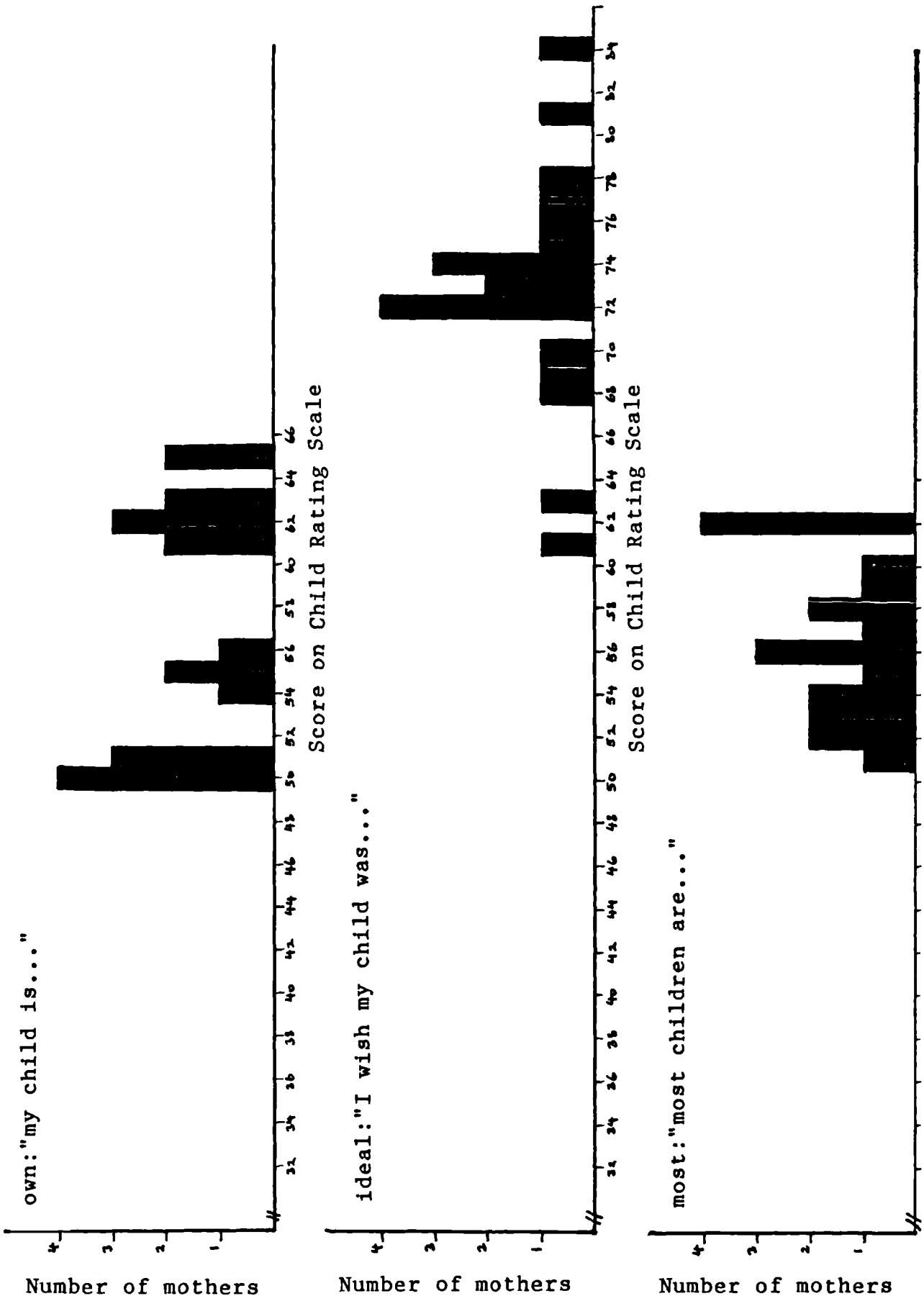
Distribution of ratings on the Child Rating Scale for

'Volunteer' Mothers - Post Test

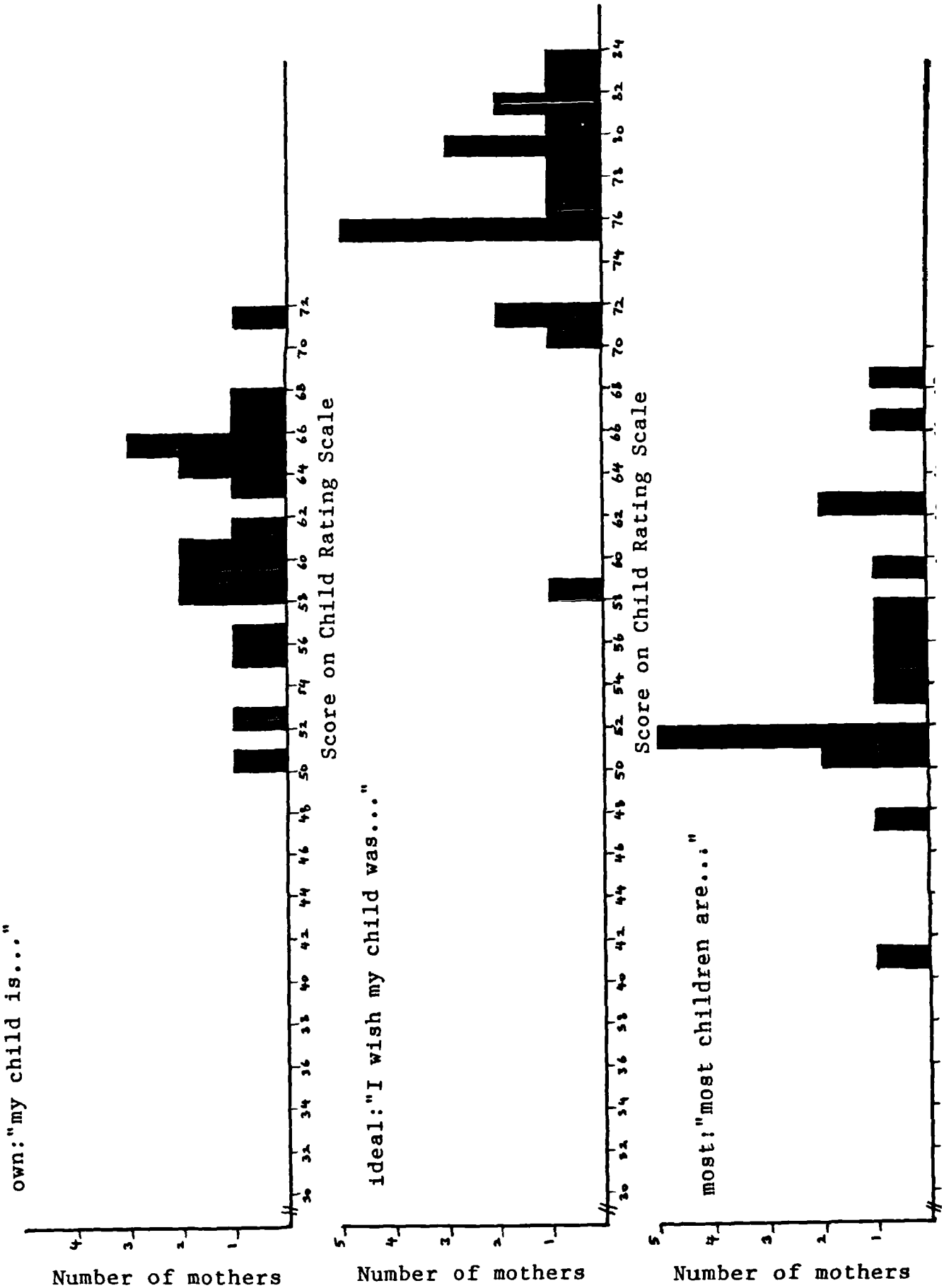


Distribution of ratings on the Child rating Scale for

'Nursery' Mothers - Pre Test

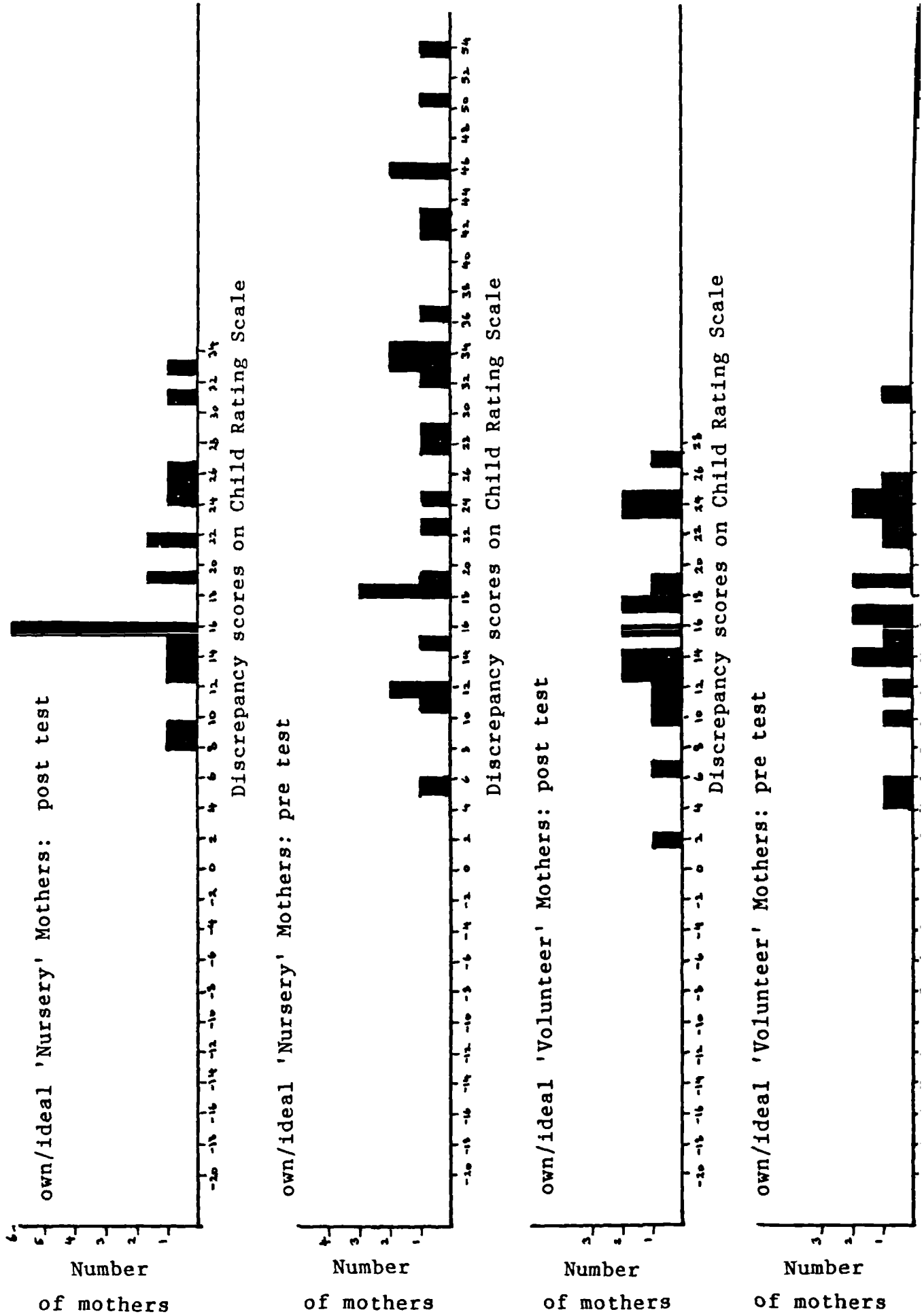


Distribution of ratings on the Child Rating Scale for 'Nursery' Mothers - Post Test

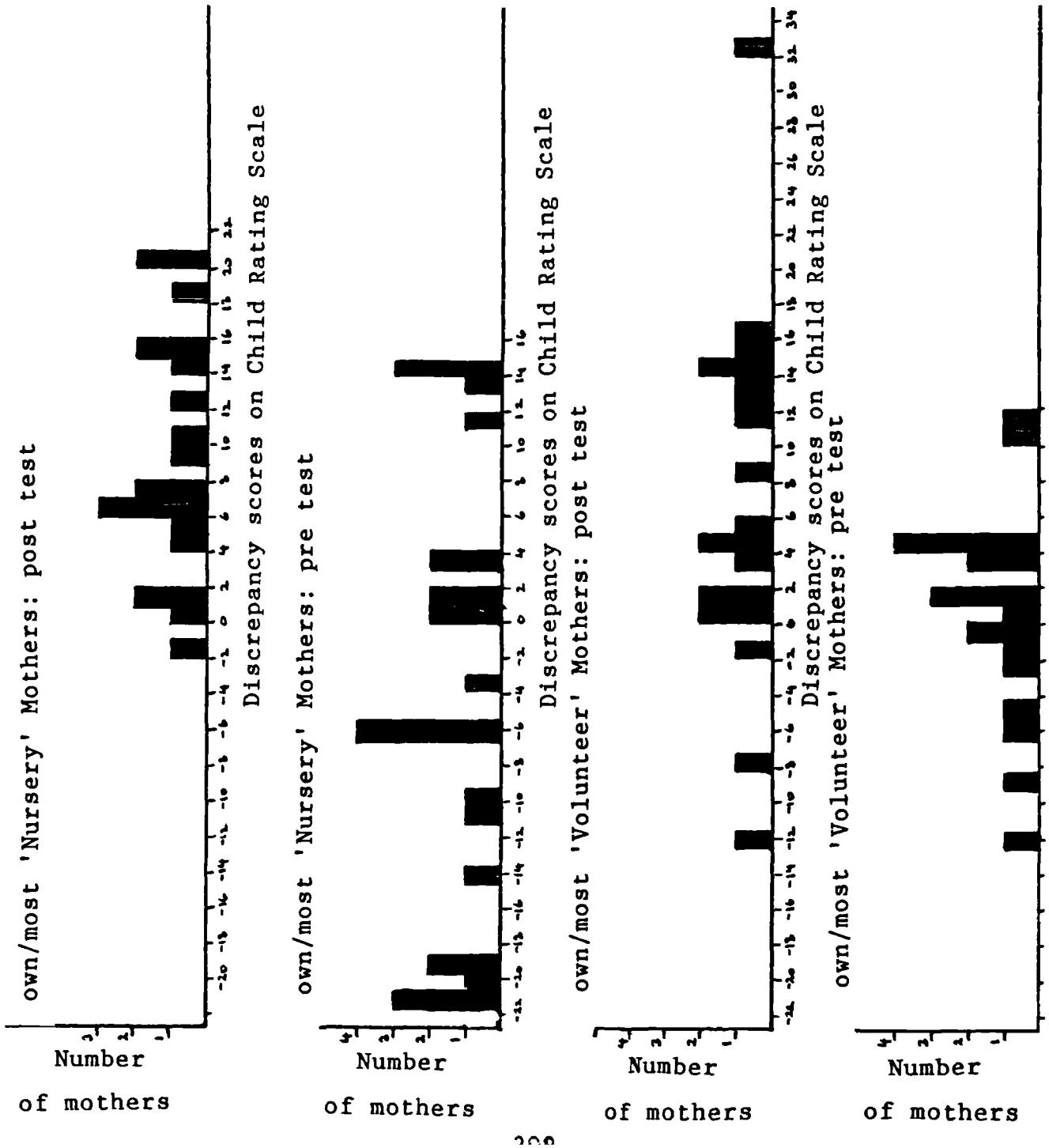


Distribution of own/ideal discrepancy scores on the Child Rating Scale :

'Volunteer' and 'Nursery' Mothers



Distribution of own/most discrepancy scores on the Child Rating Scale for 'Volunteer' and 'Nursery' Mothers



Financial Statement on CBR Programme

1. Income

a) Local:	i)	University of Guyana	G$ 8630
	ii)	Canadian International Development Agency (CIDA)	5000
			13630
b) Overseas	i)	CIDA	£2108.36
	ii)	University of London	100.00
			2208.36

Percentage breakdown of the budget:

i)	CIDA	80.5%
ii)	University of Guyana	16.1%
iii)	University of London	3.4%

2. Expenses:

a) Local:	i)	typing	G$ 1486.90
	ii)	paper, ink, stencils	3653.50
	iii)	research assistants	3360.00
	iv)	part-time lecturers	4690.00
	v)	miscellaneous	439.60
b) Overseas:	i)	materials, audio-visual and teaching aids	£ 845.86
	ii)	psychological tests and Portage materials	359.21
	iii)	books	748.49
	iv)	teaching materials	59.80
	v)	computer software	195.00

The following material is available for use with another project:

i)	audio-visual equipment	£ 326.80
ii)	psychological tests	359.21
iii)	books	748.49
iv)	computer software	195.00
	Total grant	£ 2965.58
	Materials available	1629.50
		1336.08

Cost= £ 1336.08 for 39 children for 1.25 years.
Cost= £ 27 per chid per year

(The official exchange rate, at the time of the project, was £1= G$18)

The University of Guyana
Office of the Deputy Vice-Chancellor
Professor Lennox B. Pierre

TURKEYEN CAMPUS
P.O. Box 101110 GEORGETOWN
Telephone 02—5484

Appendix XXXIX

20th September 198

Dr. Brian O'Toole is a lecturer in the Faculty of Education at the University of Guyana. He has submitted a project entitled "Validation of a Model for Community-based Rehabilitation with Pre-School Disabled Children in Guyana," for funding by the Research and Publications Committee of this institution.

The project was approved in principle, it being the unanimous opinion of the Committee that it was a worthwhile venture which would contribute in a positive way to the treatment of the disabled in these parts. But because of financial constraints the Committee could only sanction the award of eight thousand six hundred and thirty Guyana dollars ($8,630.00)* out of the total requested by Mr. O'Toole.

On behalf of the Research and Publications Committee I am directed to write in support of Dr. O'Toole's request for supplementary funding from your agency.

Professor Lennox (Prof.)
DEPUTY VICE-CHANCELLOR

* £1 =G$ 18.00

MINISTRY OF EDUCATION

Cable Address: "MINED"

P. O. Box 1014,
Georgetown,
Guyana.

IN REPLYING
QU T D E
H R F AND
No

1987-05-06

Mr Brian O'Toole
Head (Ag.) Dept. of Foundations
& Administration
University of Guyana
TURKEYEN

Dear Mr. O'Toole,

I wish to acknowledge receipt of your letter dated 87-04-14, which refers to the Community-Based Rehabilitation Programme for children with disabilities.

The Ministry shares its concern with the programme, and has nominated Cde. Norma Baichoo, Assistant Chief Education Officer (Nursery) to attend the meeting on 87-06-04.

Best of success.

Yours co-operatively,

Tessa Daniels

TESSA DANIELS
for Permanent Secretary

cc: ACEO (Nursery)

Appendix XXXXI

Evaluation of CBR programme by LSs

No.	Item	'Volunteer' VLS N=13 %	N	Nursery NLS N=16 %	N
1.	How suitable was the venue				
	suitable	62%	8	50%	8
	unsuitable	8%	1	13%	2
	N/R	31%	4	37%	6
2.	How suitable was				
	i) timing of the programme (ie at night)				
	suitable	92%	12	88%	14
	unsuitable	8%	1	12%	2
	ii) length of training sessions				
	suitable	69%	9	56%	9
	unsuitable	23%	3	31%	5
	N/R	7%	1	13%	2
	iii) length of training programme(15 mths)				
	suitable	54%	7	50%	8
	unsuitable : too long	38%	5	38%	6
	N/R	8%	1	12%	2
3.	Liked most about the training				
	learning how to help the child	8%	1	13%	2
	seeing progress in the child	15%	2	25%	4
	lectures/demonstrations	46%	6	6%	1
	child's interest in the visits	8%	1	13%	2
	other	23%	3	38%	6
	N/R			6%	1
4.	What disliked most about programme				
	parents not being at home	8%	1	13%	2
	assessments being done	15%	2	6%	1
	visiting homes			25%	4
	nothing	54%	7	13%	2
	other	23%	2	25%	4
	N/R			19%	3
5.	How could programme be improved (more than one idea possible)				
	more film shows				2
	more resource persons		1		3
	establish special school in village		1		4
	more training				2
	more education of community		2		2
	other		5		1
	N/R		4		2

No.	Item	VLS		NLS	
6.	What else should the course cover				
	more practical demonstrations	8%	1	13%	2
	experience at special schools			13%	2
	nothing	84%	11	50%	8
	other			13%	2
	N/R	8%	1	13%	2
7.	What could have been left out				
	nothing	85%	11	75%	12
	N/R	15%	2	25%	4
8.	Was training programme too long				
	Yes	23%	3	19%	3
	No	77%	10	81%	13
9.	Was training presented at an appropriate level of difficulty				
	Yes	77%	10	38%	6
	No	15%	2	25%	4
	N/R	8%	1	38%	6
10.	Do you have a better idea of what to expect from the child				
	Yes	92%	12	88%	14
	No			6%	1
	N/R	8%	1	6%	1
11.	Are you noticing more detail re N				
	Yes	92%	12	94%	15
	No	8%	1	6%	1
12.	Are you more confident about assisting children				
	Yes *	100%	13	81%	13
	No			6%	1
	N/R			12%	2
	* I know where to start helping.. understand children better now..can prepare appropriate materials now.. more observant				
13.	Are you structuring play more now				
	Yes	85%	11	75%	12
	No	15%	2	6%	1
	N/R			19%	3
14.	Are you focussing on particular activities				
	Yes	77%	10	56%	9
	No	8%	1	6%	1
	N/R	15%	2	38%	6

No	Item	VLS		NLS	
15.	What is the main aim of the programme (more than one idea possible)				
	learn about disability		1		1
	help disabled children generally		5		6
	integrate disabled children		5		4
	help disabled children acquire specific skills		1		3
	help disabled people be more independent		1		1
	help parents work with their children		1		1
	other		2		3
16.	Do you see any improvements in the child				
	Yes	85%	11	100%	16
	No	8%	1		
	N/R	8%	1		
17.	What impact has the programme had on mother				
	grateful for help	31%	4	69%	11
	increased acceptance of the child	31%	4		
	very little	15%	2	13%	2
	other	15%	2	13%	2
	N/R	8%	1	6%	1
18.	What do mothers regard as main aim of the programme				
	help child generally	31%	4	31%	5
	help in specific area			13%	2
	help child become normal	23%	3	13%	2
	assist family in caring for child			19%	3
	other	31%	4	19%	3
	N/R	15%	2	6%	1
19.	Are other family members now more involved with the child				
	Yes *	54%	7	56%	9
	No	23%	3	13%	2
	D/K	8%	1	19%	3
	N/R	15%	2	13%	2
	* help in making aids..help with physical exercises..ensure child does work given by LS				
20.	Have others commented on changes seen in the child				
	Yes	85%	11	44%	7
	No	8%	1	19%	3
	D/K	8%	1	6%	1
	N/R			31%	5

No.	Item	VLS		NLS	
21.	Has the community been affected by the programme				
	Yes *	46%	6	13%	2
	No **	38%	5	69%	11
	D/K	15%	2		
	N/R			19%	3
	* neighbours now more concerned				
	** people still don't care in the community				
22./23.	Which parts of the programme have been difficult to implement and why				
	visiting the homes	8%	1	25%	4
	interviews, questionnaires			13%	2
	family co-operation	15%	2	13%	2
	none	23%	3	19%	3
	other	31%	4	13%	2
	N/R	23%	3	19%	3
24.	Which aspect of the programme is most important				
	practical work with the child	8%	1	25%	4
	going into the homes	38%	5	25%	4
	working with a family member	23%	3		
	other	31%	4	6%	1
	N/R			44%	7
25.	Which is the least important				
	none	85%	11	88%	14
	assessments	8%	1	6%	1
	diary observations	8%	1	6%	1
26.	How helpful were the WHO Manuals				
	very helpful	85%	11	50%	8
	quite helpful			13%	2
	not helpful				
	N/R	15%	2	37%	6
27.	How valuable was the supervision you received on the course				
	very helpful	100%	13	44%	7
	quite helpful			13%	2
	not helpful				
	N/R			44%	7
28	How helpful was the CBR project				
	very helpful	85%	11	37%	6
	quite helpful			19%	3
	not helpful				
	N/R	15%	2	44%	7

No.	Item	VLS		NLS	
29.	What, if anything, have you gained from the programme				
	more sensitive to child's needs	15%	2	13%	2
	knowledge about disabled children	31%	4	19%	3
	become a better person	15%	2	6%	1
	learned patience			13%	2
	other	23%	3	19%	3
	N/R	15%	2	31%	5
30.	How realistic is it to make mothers into more effective teachers				
	very realistic	31%	4	19%	3
	quite realistic	46%	6	19%	3
	not realistic				
	other			13%	2
	N/R	23%	3	50%	8
31.	Have community attitudes changed as a result of the programme				
	Yes *	46%	6	31%	5
	No	23%	3	13%	2
	to some extent **	23%	3		
	N/R	8%	1	56%	9
	* other children are now playing with N people don't feel so ashamed of their handicap				
	** there have been some changes but the programme is new and change is slow				
32.	How many children could one LS work with				
	1	31%	4	25%	4
	2	31%	4	13%	2
	3	23%	3		
	4	8%	1	6%	1
	5+			13%	2
	N/R	8%	1	44%	7
33.	Would you want to be involved in such a programme again				
	Yes	92%	12	37%	6
	No			13%	2
	uncertain			13%	2
	N/R	8%	1	37%	6

Appendix XXXXII

Independent Reliability Checks on Griffiths Assessments

Subject	Pre/Post*	Researcher's assessment	Independent evaluation	Differences between scores	% of score of researche
32	Pre	67	72	5	7.5%
34	Pre	110	106	4	3.6%
38	Pre	116	108	8	6.9%
55	Pre	88	92	4	4.5%
2a	Post	88	85	3	3.4%
5a	Post	79	71	8	10.1%
10b	Post	90	95	5	5.5%
15	Post	50	44	6	12.0%
30a	Post	93	90	3	3.2%

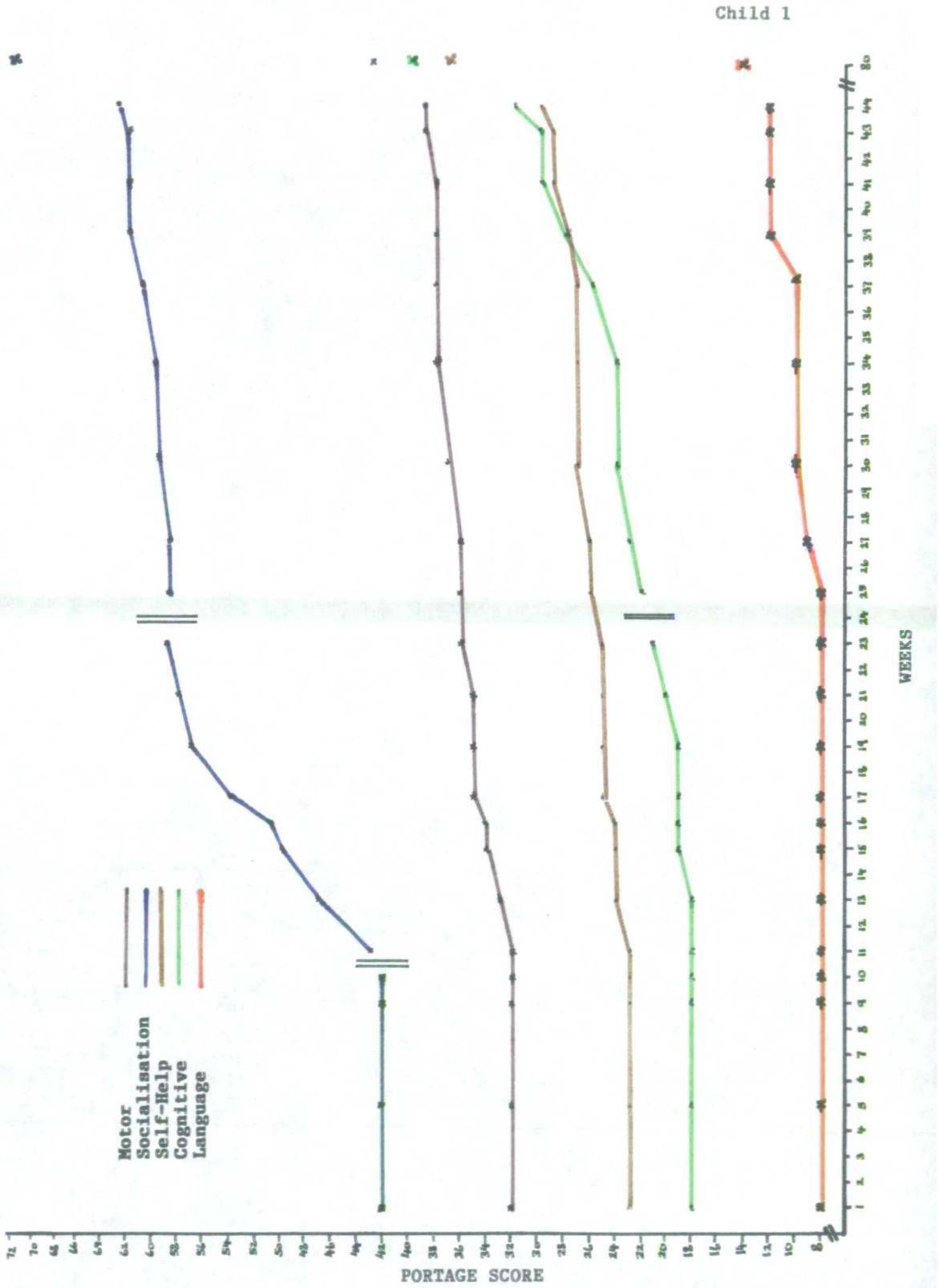
Results of Independent Evaluators' assessments of LSs

No.	Item	Volunteer N=16 %	Volunteer N=16 N	Nursery N=12 %	Nursery N=12 N
1.	Portage area adopted				
	Language	38%	6	58%	7
	Self-Help				
	Motor	19%	3		
	Cognitive	19%	3	42%	5
	Socialisation	25%	4		
2.	Description of aids used with child				
	commercially produced	13%	2		
	home-made	50%	8	42%	5
	none used	31%	5	50%	6
	N/R	6%	1	8%	1
3.	Most positive feature of session				
	patience	13%	2	17%	2
	organisation	19%	3	8%	1
	sensitivity	19%	3	17%	2
	confidence	13%	2	8%	1
	other	13%	2	17%	2
	N/R	25%	4	33%	4
4.	Most negative feature of session				
	disorganised	19%	3	25%	3
	insensitive to child's needs			17%	2
	low confidence			17%	2
	low understanding of task	6%	1	17%	2
	other	19%	3	8%	1
	none	56%	9	17%	2
5.	LS appeared confident				
	strongly agree	50%	8	8%	1
	agree	19%	3	50%	6
	uncertain	19%	3	8%	1
	disagree	13%	2	25%	3
	strongly disagree			8%	1
6.	LS formed good rapport with mother				
	strongly agree	56%	9	17%	2
	agree	25%	4	50%	6
	uncertain	6%	1	25%	3
	disagree	13%	2	8%	1
	strongly disagree				

No	Item	VLS		NLS	
6b.	LS formed good rapport with child				
	strongly agree	38%	6	17%	2
	agree	38%	6	66%	8
	uncertain	13%	2	17%	2
	disagree	13%	2		
	strongly disagree				
7.	LS prepared definite activity				
	strongly agree	31%	5	8%	1
	agree	31%	5	17%	2
	uncertain	13%	2	50%	6
	disagree	25%	4	25%	3
	strongly disagree				
8.	Materials were of an appropriate level				
	strongly agree	19%	3	8%	1
	agree	38%	6	33%	4
	uncertain	13%	2	42%	5
	disagree	13%	2	17%	2
	strongly disagree	19%	3		
9.	LS aware of their role				
	strongly agree	38%	6		
	agree	31%	5	33%	4
	uncertain	6%	1	50%	6
	disagree	13%	2	17%	2
	strongly disagree	13%	2		
10.	LS understands child's difficulty				
	strongly agree	56%	9	25%	3
	agree	13%	2	50%	6
	uncertain	13%	2	8%	1
	disagree	6%	1	17%	2
	strongly disagree	13%	2		
11.	Portage Test done effectively				
	strongly agree	38%	6	17%	2
	agree	25%	4	50%	6
	uncertain	6%	1	25%	3
	disagree	19%	3	8%	1
	strongly disagree	13%	2		
12.	LS adopts clear procedure				
	strongly agree	44%	7		
	agree	19%	3	33%	4
	uncertain	6%	1	25%	3
	disagree	31%	5	25%	3
	strongly disagree			17%	2

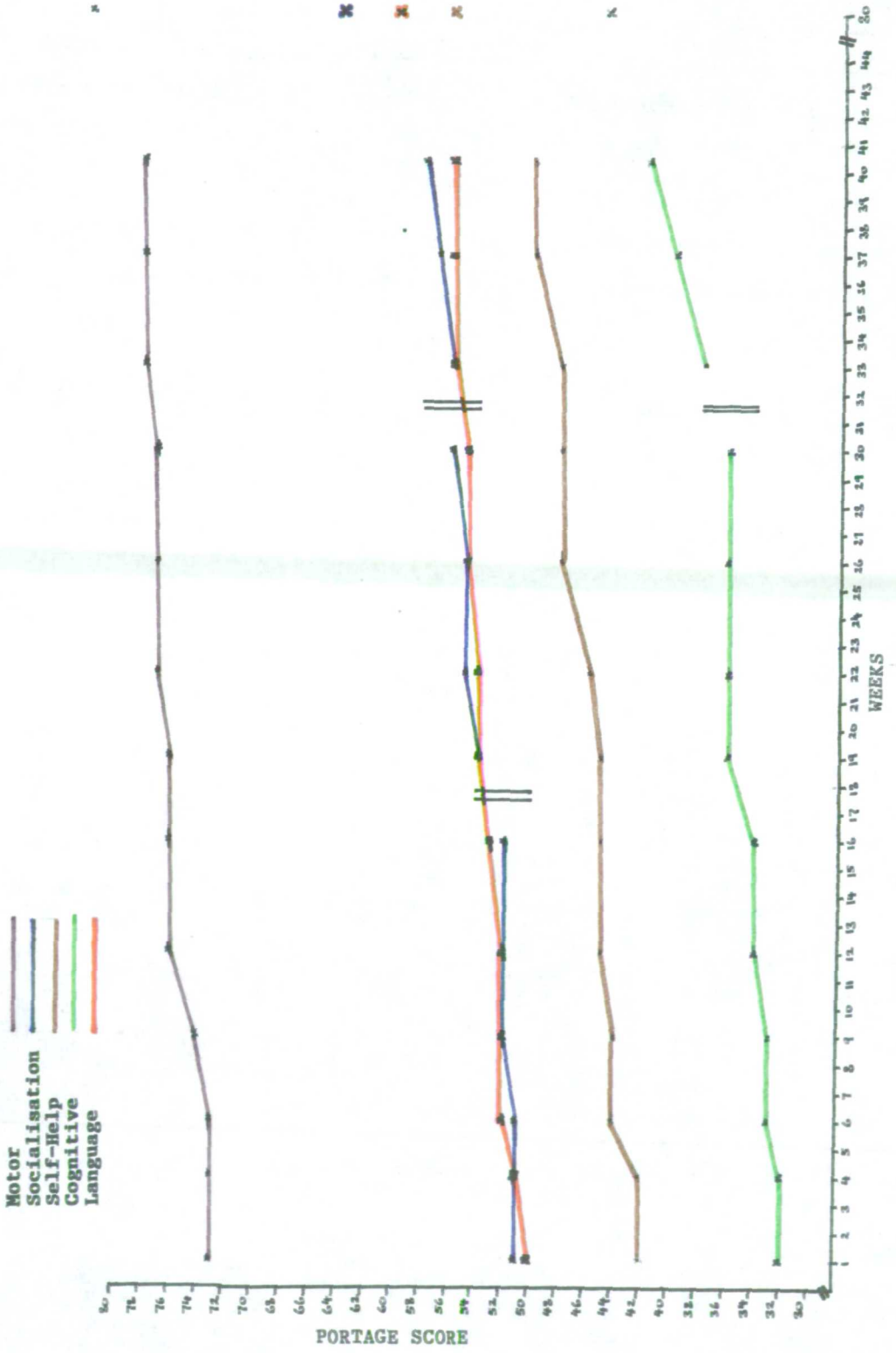
No.	Item	VLS		NLS	
13.	LS involved in task				
	strongly agree	56%	9	17%	2
	agree	13%	2	42%	5
	uncertain	13%	2	8%	1
	disagree	13%	2	33%	4
	strongly disagree	6%	1		
14.	Overall assessment				
	strongly agree	50%	8	17%	2
	agree	19%	3	50%	6
	uncertain	19%	3	25%	3
	disagree	13%	2	8%	1
	strongly disagree				

Acquisition of Portage Items over time



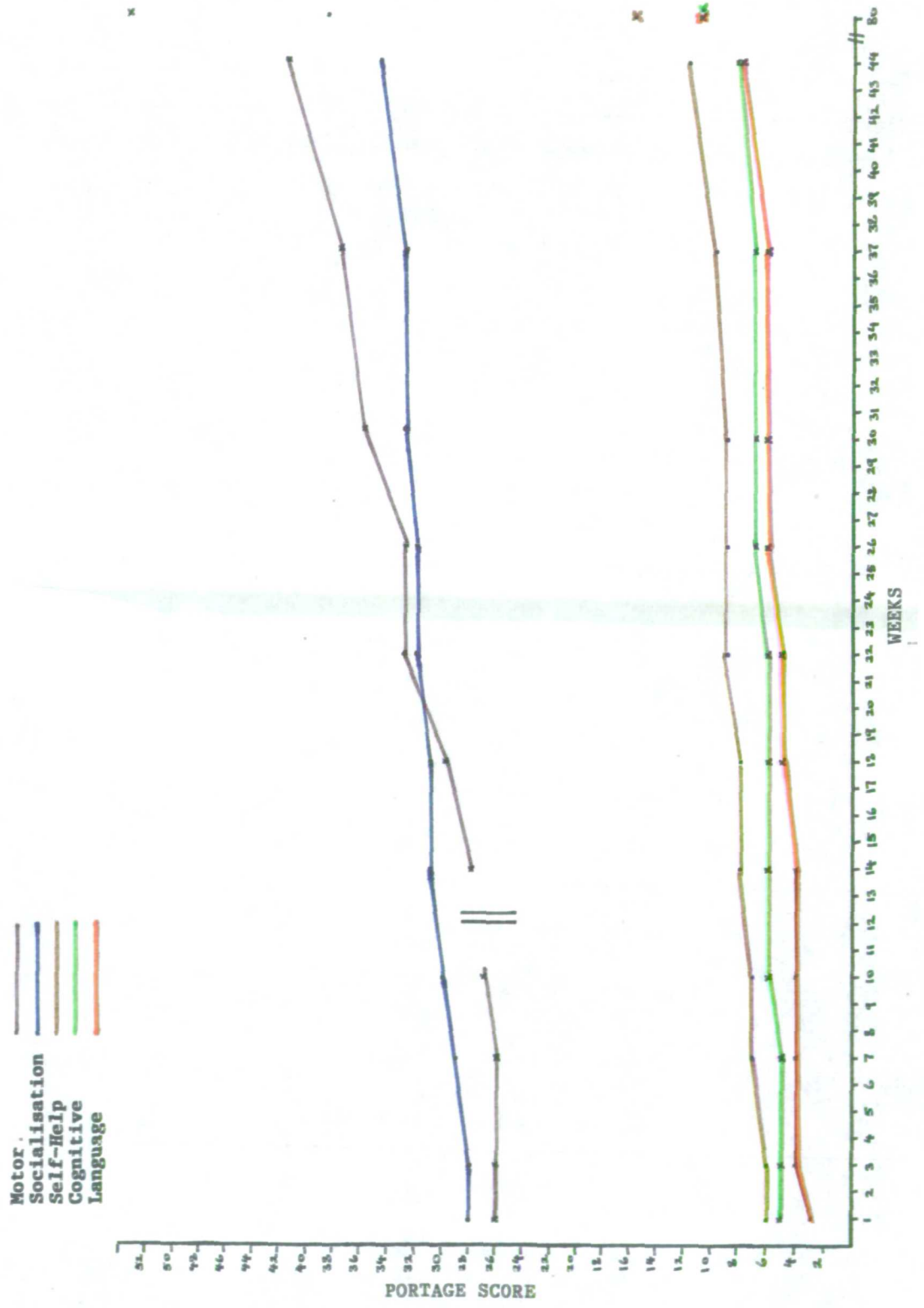
Acquisition of Portage Items over time

Child 2



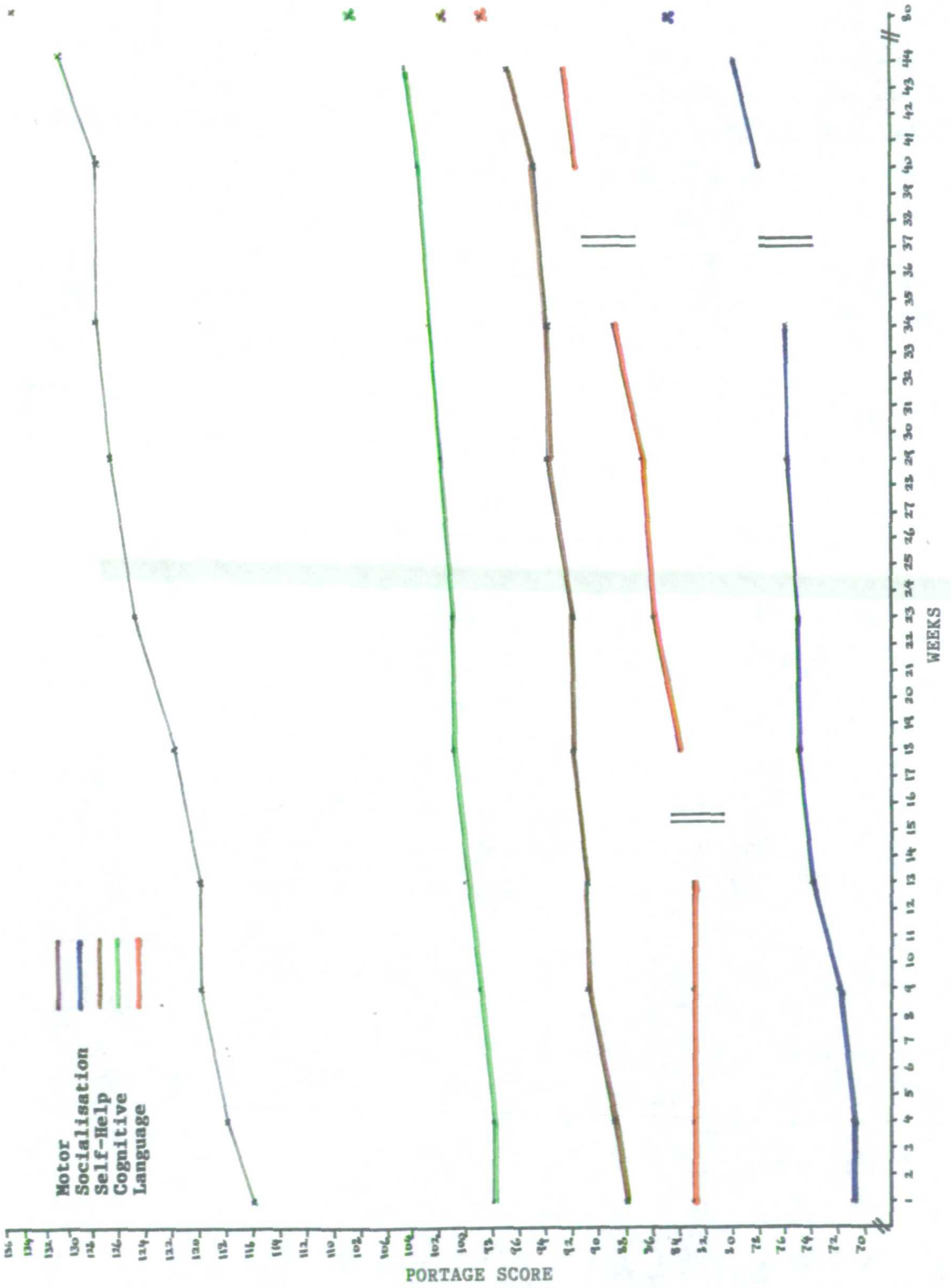
Acquisition of Portage Items over time

Child 3



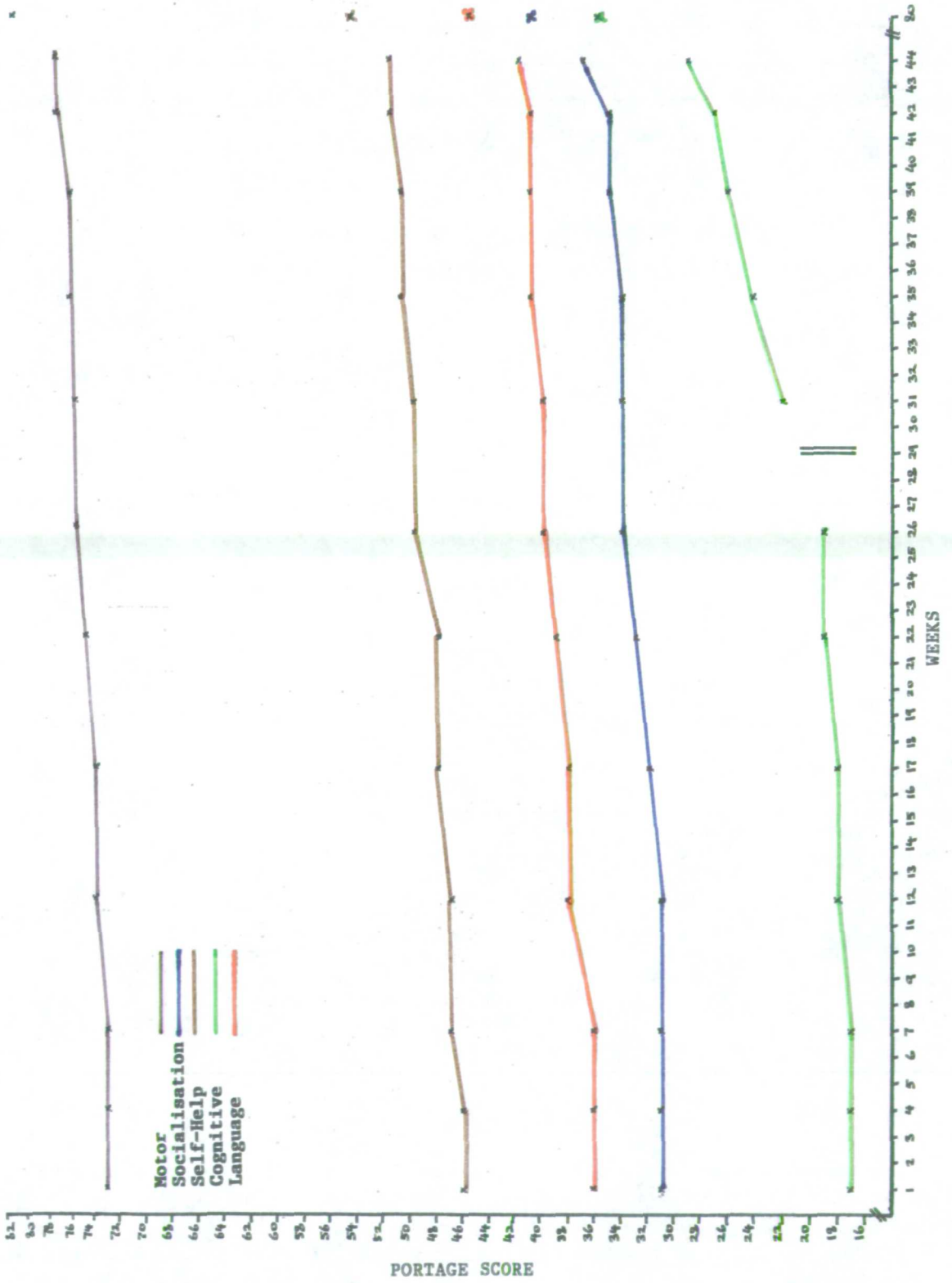
Acquisition of Portage Items over time

Child 4



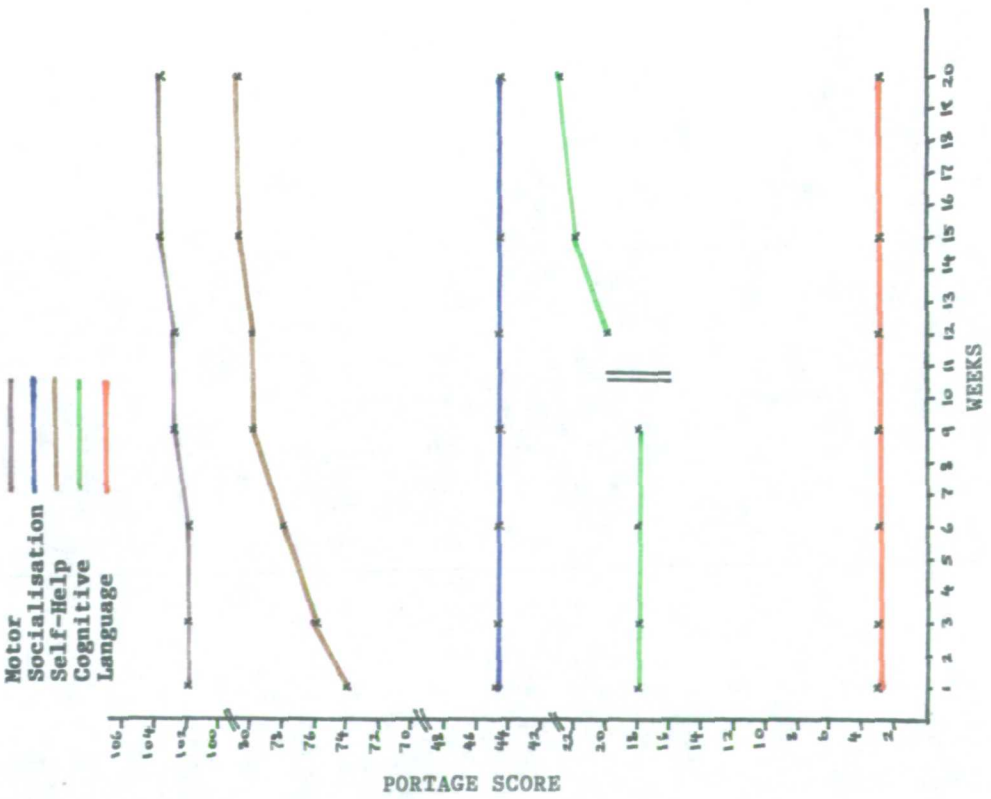
Acquisition of Portage Items over time

Child 5



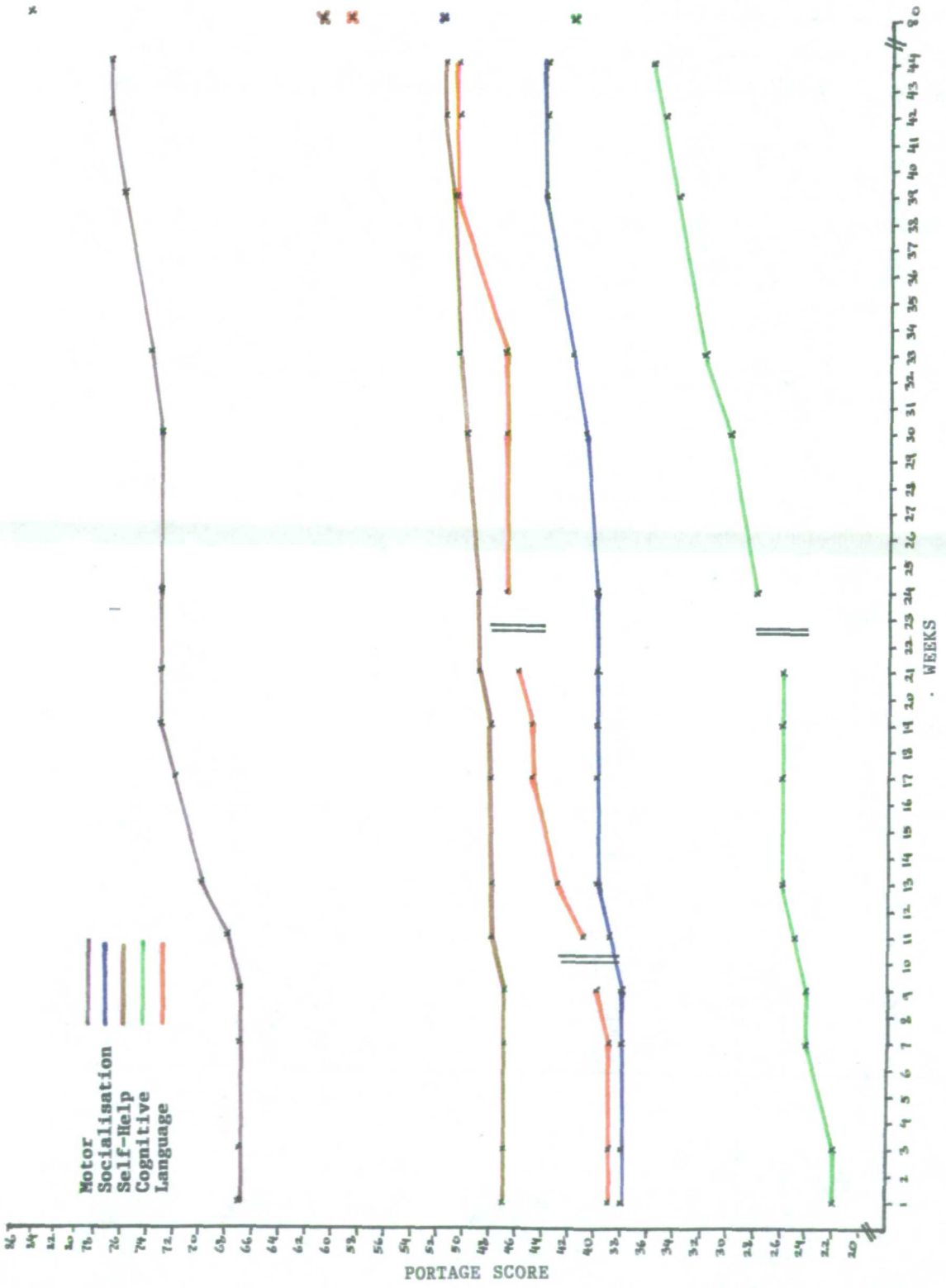
Acquisition of Portage Items over time

Child 6



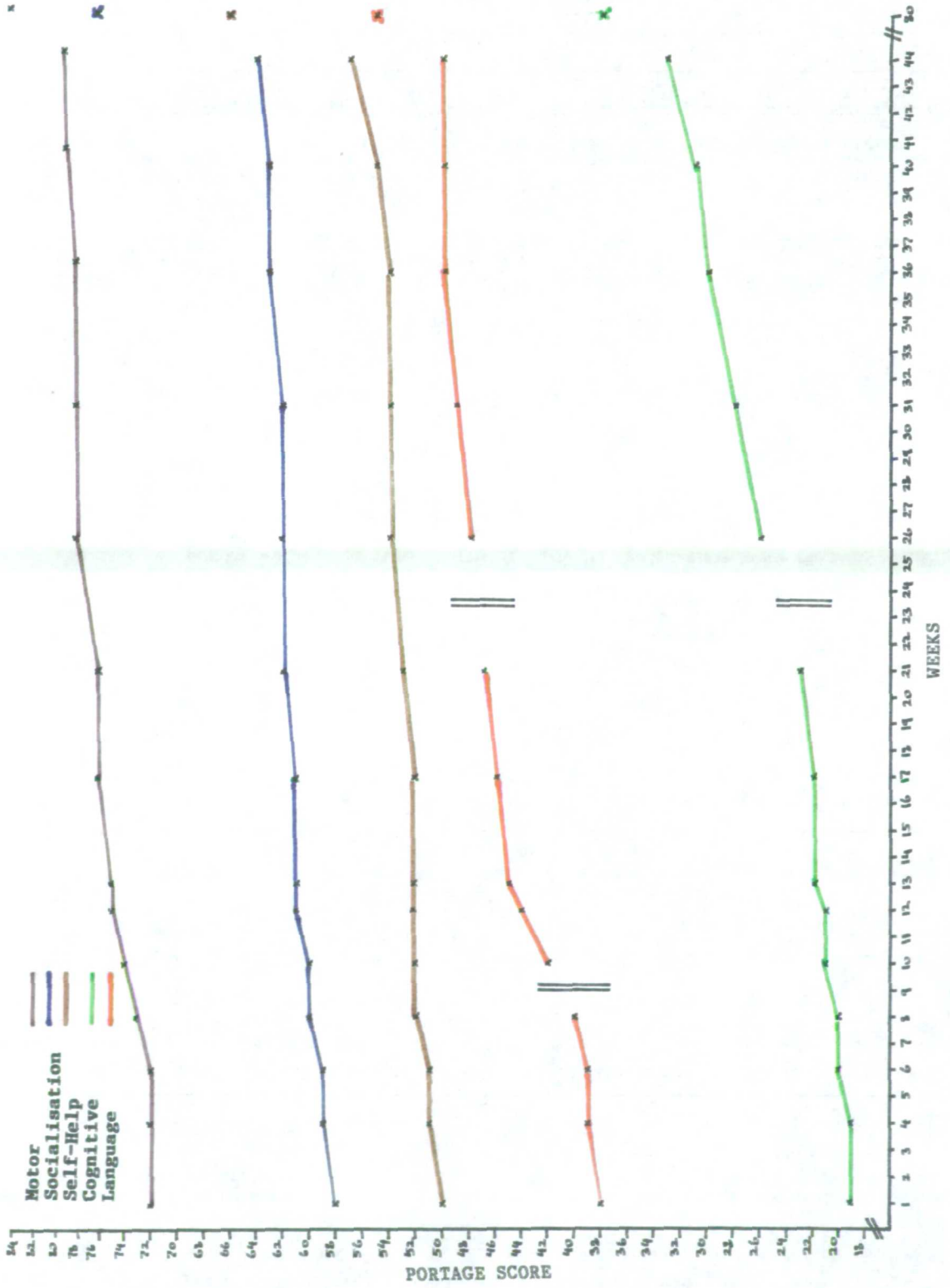
Acquisition of Portage Items over time

Child 7



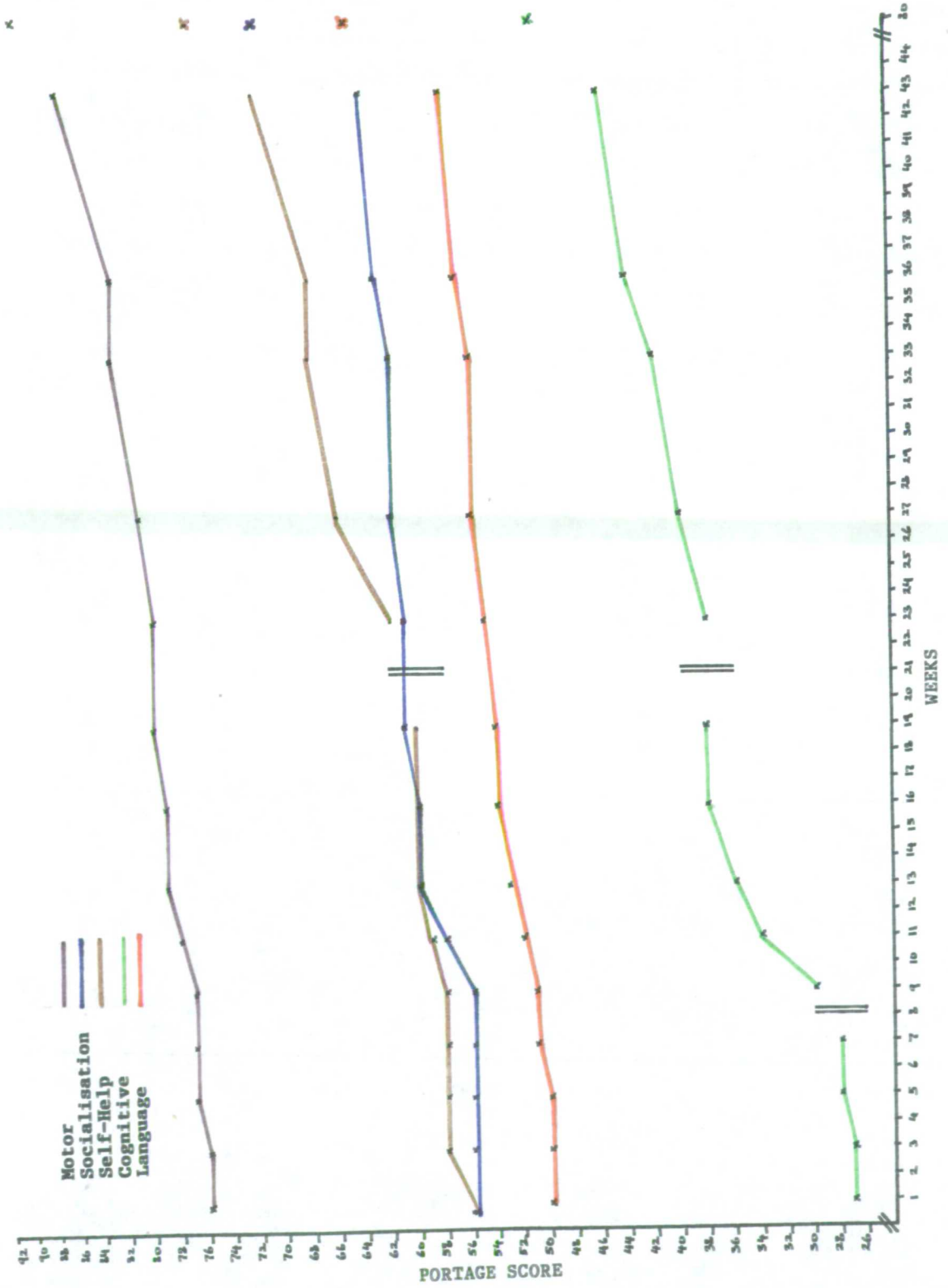
Acquisition of Portage Items over time

Child 8



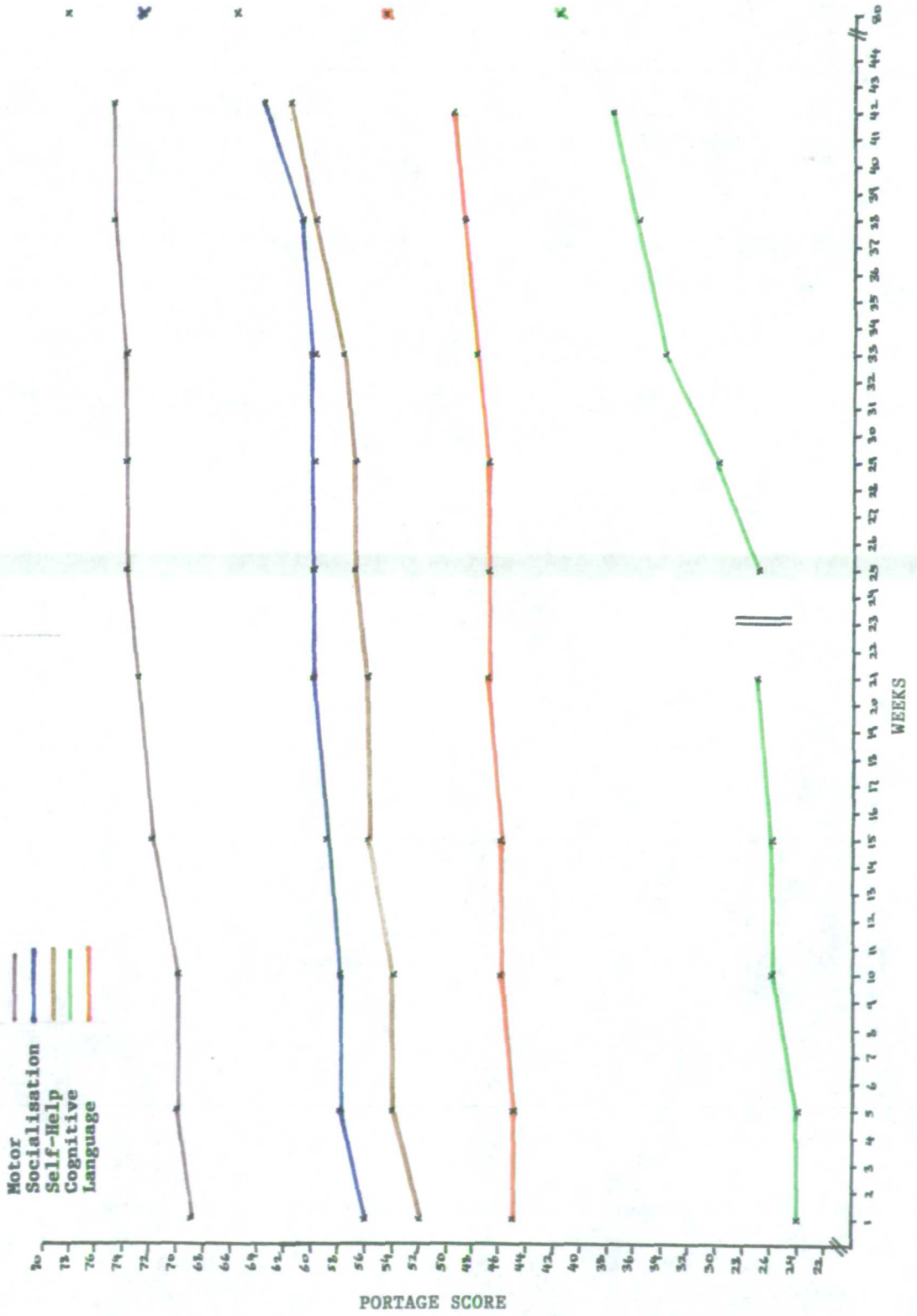
Acquisition of Portage Items over time

Child 9



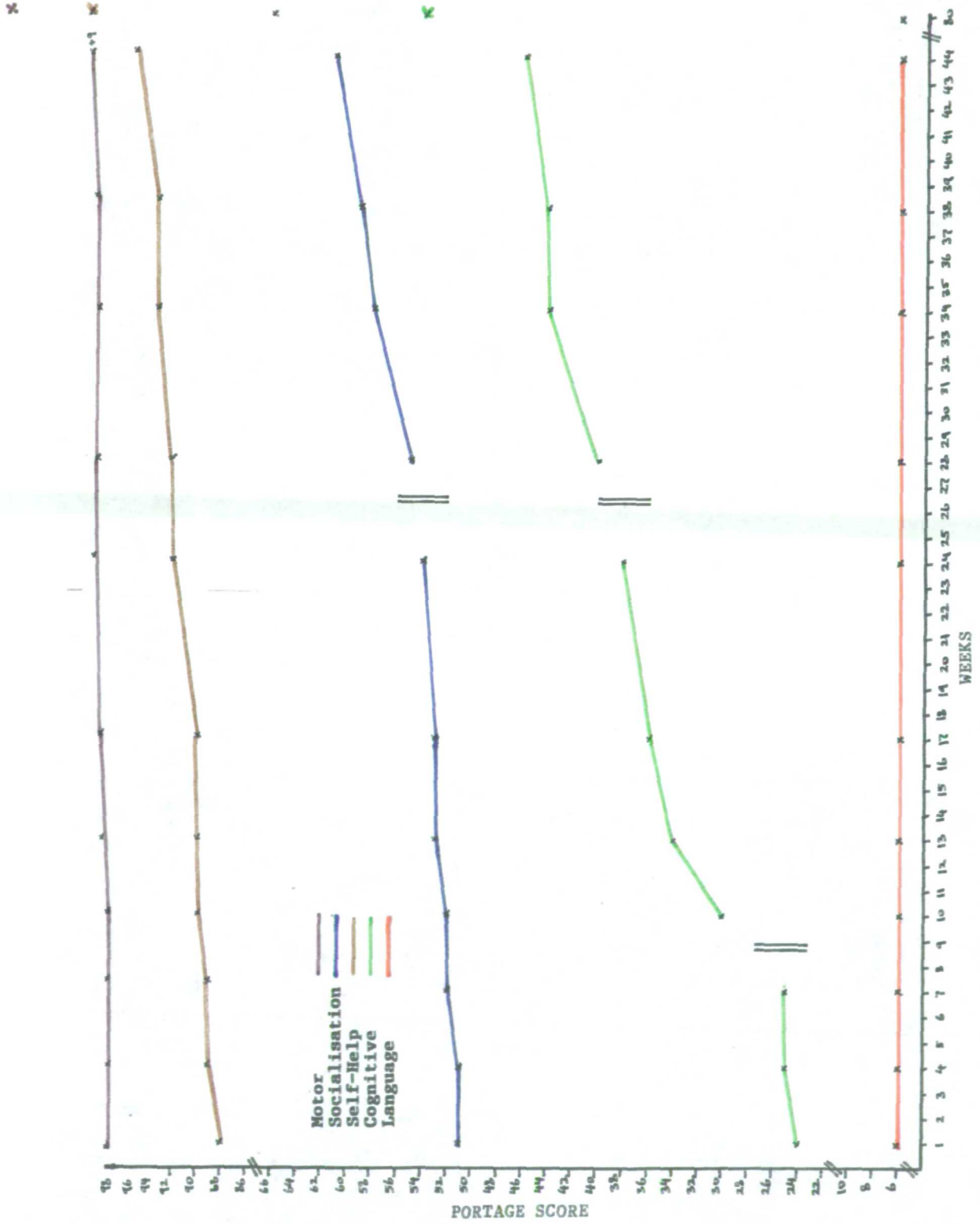
Acquisition of Portage Items over time

Child 10



Acquisition of Portage Items over time

Child 11



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